

# Health and Human Rights Journal

JUNE 2019, VOLUME 21, NUMBER 1

## SPECIAL SECTIONS

### Global Health Fieldwork Ethics and Human Rights

#### GUEST EDITORS

Rachel Hall-Clifford, David Addiss, Robert Cook-Deegan, and James V. Lavery

### Invoking Health and Human Rights in the United States

#### GUEST EDITOR

Sarah S. Willen

#### *Publisher*

Harvard FXB Centre for Health and Human Rights

#### *Editor-in-Chief*

Paul Farmer

#### *Executive Editor*

Carmel Williams

#### *Senior Editor*

Jessica Moore Kaplan

#### *Copy Editors*

Morgan Stoffregen  
Jessica Moore Kaplan

#### *Contributing Editor*

Arlan Fuller

#### *Designer*

Catlin Rockman

## ABOUT THE JOURNAL

*Health and Human Rights Journal* began publication in 1994 under the editorship of Jonathan Mann, who was succeeded in 1997 by Sofia Gruskin. Paul Farmer, co-founder of Partners In Health, assumed the editorship in 2007. *Health and Human Rights Journal* is an open access online publication and a leading forum of debate on global health and rights concerns. The journal maintains a tradition of critical scholarship and also provides an inclusive forum for action-oriented dialogue among human rights practitioners, with peer-reviewed articles focusing rigorous scholarly analysis on the conceptual foundations and challenges of rights discourse and action in relation to health.

*Health and Human Rights Journal* is listed in PubMed, the database of the National Library of Medicine.

## PUBLICATION POLICY

*Health and Human Rights Journal* welcomes unsolicited manuscripts on an ongoing basis. Submissions should not exceed 7000 words, while submissions to the Perspectives section should not exceed 2000 words. Book reviews and Letters to the Editor are also welcome. More information on submissions is available at <http://www.hhrjournal.org/submissions>.

Please submit manuscripts through the website or by email to [HHRSubmissions@hsph.harvard.edu](mailto:HHRSubmissions@hsph.harvard.edu). Author guidelines are available on the *Health and Human Rights* website (<http://www.hhrjournal.org>). Views expressed in the journal are those of the authors and do not necessarily reflect the views of the publisher, editors, editorial board members, or other members.

## COPYRIGHT POLICY

*Health and Human Rights Journal* applies the Creative Commons Attribution-Noncommercial 3.0 Unported License to all articles, with the philosophy that there should be no financial barriers to access information. The Attribution-Noncommercial license (<http://creativecommons.org/licenses/by-nc/3.0/>) lets people freely copy, distribute, remix, and build upon contributors' work, provided it is not used to make a profit and the original authors and *Health and Human Rights Journal* are appropriately acknowledged. These conditions can be waived if author, as copyright holder, grants potential users explicit permission. Copyrighted material may be included in articles provided authors provide proof of written permission for such use from the copyright holder.

## OPEN ACCESS POLICY

*Health and Human Rights Journal* does not charge authors article processing fees unless authors can utilize an institutional open access publishing grant. Many institutions and research facilities have funding grants available to support publication in open access journals. If authors cannot access OA grants, article processing fees are waived by HHR. Authors are asked whether they can pay this fee only after a paper is accepted for publication, and inability to pay will not impact publication. When authors are able to use open access funds the article processing fee is US\$2,000.

## BACK ISSUES

As an open access publication, the *Health and Human Rights Journal* is not available by subscription. All content is available free of charge at [www.hhrjournal.org](http://www.hhrjournal.org), including back issues since Volume 1, Number 1 (1994). Back issues are also available through JSTOR, the not-for-profit online digital archive. Users at institutions that participate in JSTOR's Arts & Sciences Complement Collection can access back issues directly by visiting the *Health and Human Rights Journal* information page at JSTOR. For more information on JSTOR, please visit <http://www.jstor.org>.

*Health and Human Rights Journal* (online) ISSN 2150-4113

## MASTHEAD

*Publisher*  
Harvard FXB Centre  
for Health and Human Rights

*Editor-in-Chief*  
Paul E. Farmer

*Executive Editor*  
Carmel Williams

*Senior Editor*  
Jessica Moore Kaplan

*Contributing Editor*  
Arlan Fuller

### *Executive Editorial Board*

Cathy Albisa  
Jacqueline Bhabha  
Oscar Cabrera  
Audrey Chapman  
Martha Davis  
Sheila Davis\*  
Linda Fried  
Varun Gauri  
Howard Hu  
Jennifer Leaning  
Emmanuel Kabengele Mpinga  
Chidi Odinkalu  
Jacqueline Pitangy  
Eric Stover  
Alicia Ely Yamin

### *Editorial Board*

Philip Alston  
Agnès Binagwaho  
Manuel Carballo  
Brian E. Concannon Jr.  
Lawrence Cox  
Ernest Drucker  
Harvey Fineberg  
Julio Frenk  
H. Jack Geiger  
Lawrence Gostin\*  
Sofia Gruskin  
Timothy Harding  
Aart Hendriks  
Paul Hunt  
Michael D. Kirby  
Adetokunbo O. Lucas  
Rakiya Omaar  
Richard Parker  
Thomas Pogge  
Julieta Rossi  
Barbara Rylko-Bauer  
Margaret L. Satterthwaite  
Haun Saussy  
Michael Selgelid  
Amartya Sen  
Gracelyn Smallwood  
Margaret A. Somerville  
Henry J. Steiner  
Bryan Stevenson  
Daniel Tarantola  
Monika Kalra Varma  
Gavin Yamey

\*An asterisk denotes members of the Harvard FXB *Health and Human Rights* Publishing Consortium (see below)

*Founding Editor*  
Jonathan Mann, 1994–1998

## HHR CONSORTIUM MEMBERS

HHR's open access policy is made possible through the generous support of Harvard University Press, The FXB Center for Health and Human Rights, and our institutional consortium members. These include:

- Partners in Health, Boston
- Dalla Lana School of Public Health, University of Toronto
- Mailman School, Columbia University, New York
- The Task Force for Global Health, USA
- O'Neill Institute for National and Global Health Law, Georgetown University, Washington, D.C.
- UNAIDS, Geneva

## EDITORIAL OFFICE

*Health and Human Rights Journal*  
François-Xavier Bagnoud Center for Health and Human Rights  
Harvard School of Public Health  
651 Huntington Avenue, 7th Floor  
Boston, MA 02115, USA  
Tel: (1) 617.432.0656  
Fax: (1) 617.432.4310  
Website: <http://www.hhrjournal.org>  
Email: [hhrjournal@hsph.harvard.edu](mailto:hhrjournal@hsph.harvard.edu)

## Table of Contents

### SPECIAL SECTION ON GLOBAL HEALTH FIELDWORK ETHICS AND HUMAN RIGHTS

*In collaboration with Agnes Scott College, the Task Force for Global Health, and Emory University Rollins School of Public Health*

- |    |  |     |  |
|----|--|-----|--|
| 1  | EDITORIAL<br>Global Health Fieldwork Ethics: Mapping the Challenges<br><i>Rachel Hall-Clifford, David G. Addiss, Robert Cook-Deegan, and James V. Lavery</i>   | 81  | Ethical Considerations for Disseminating Research Findings on Gender-Based Violence, Armed Conflict, and Mental Health: A Case Study from Rural Uganda<br><i>Jennifer J. Mootz, Lauren Taylor, Milton L. Wainberg, and Kaveh Khoshnood</i> |
| 7  | Ethically Managing Risks in Global Health Fieldwork: Human Rights Ideals Confront Real World Challenges<br><i>Rachel Hall-Clifford and Robert Cook-Deegan</i>  | 93  | Documenting the Impact of Conflict on Women Living in Internally Displaced Persons Camps in Sri Lanka: Some Ethical Considerations<br><i>Shana Swiss, Peggy J. Jennings, K. G. K. Weeraratne, and Lori Heise</i>                           |
| 19 | Apology and Unintended Harm in Global Health<br><i>David G. Addiss and Joseph J. Amon</i>  | 103 | Witnessing Obstetric Violence during Fieldwork: Notes from Latin America<br><i>Arachu Castro</i>   |
| 33 | An Assessment of Human Rights-Based Approaches to Health Knowledge, Attitudes, and Practices Among Centers for Disease Control and Prevention Locally Employed Staff<br><i>Izraelle McKinnon, Aun Lor, and Dabney P. Evans</i> | 115 | The Lived Experience of Global Public Health Practice: A Phenomenological Account of Women Graduate Students<br><i>Corey McAuliffe, Ross Upshur, Daniel W. Sellen, and Erica Di Ruggiero</i>   |
| 45 | COMMENTARY<br>Institutionalizing Ethical Review in Global Health Practice: A Modest Proposal<br><i>David Ross</i>  | 129 | COMMENTARY<br>Where There Is No Hashtag: Considering Gender-Based Violence in Global Health Fieldwork in the Time of #MeToo<br><i>Rachel Hall-Clifford</i>   |
| 49 | Ethics of Global Health Photography: A Focus on Being More Human<br><i>Aubrey Graham, James V. Lavery, and Robert Cook-Deegan</i>  | 133 | COMMENTARY<br>#MeToo Meets Global Health: A Call to Action<br><i>A statement by participants of the global health fieldwork ethics workshop, April 2018</i>  |
| 63 | Results Communication in Breast Milk Biomonitoring Studies: A Scoping Review and Stakeholder Consultation<br><i>Alyssa Mari Thurston, Federico Andrade-Rivas, and Jerry M. Spiegel</i>   | 141 | STUDENT PAPER<br>Ethical Challenges in Medical Community Internships: Perspectives from Medical Interns in the Philippines<br><i>Aimee Lorraine C. Capinpuyan and Red Thaddeus D. Miguel</i>   |

- 149 STUDENT PAPER  
Addressing Ethical Quandaries in  
Undergraduate Student-Led Global Health  
Trips: Design, Implementation, and  
Challenges of Guidelines by Students for  
Students  
*Jacob Roble, Laura Block, Mason Flannagan,  
Eric Obschering, and Lori Diprete Brown*

## SPECIAL SECTION ON INVOKING HEALTH AND HUMAN RIGHTS IN THE UNITED STATES

- 157 INTRODUCTION  
Invoking Health and Human Rights in the  
United States: Museums, Classrooms, and  
Community-Based Participatory Research  
*Sarah S. Willen*
- 163 Health Is a Human Right—at CDC?  
*Sarah S. Willen*
- 179 Mobilizing Health Metrics for the Human  
Right to Water in Flint and Detroit, Michigan  
*Nadia Gaber*
- 191 Teaching Health as a Human Right in the  
Undergraduate Context: Challenges and  
Opportunities  
*Bisan A. Salhi and Peter J. Brown*

## GENERAL PAPERS

- 203 Tomorrow's Stewards: The Case for a  
Unified International Framework on the  
Environmental Rights of Children  
*Karen E. Makuch, Sunya Zaman, and Miriam  
R. Aczel*
- 215 Asylum Medicine: Standard and Best  
Practices  
*Hope Ferdowsian, Katherine McKenzie, and  
Amy Zeidan*

- 227 The Role of Gender in the Health and Human  
Rights Practices of Police: The SHIELD Study  
in Tijuana, Mexico  
*Teresita Rocha-Jiménez, Maria Luisa Mittal,  
Irina Artamonova, Pieter Baker, Javier Cepeda,  
Mario Morales, Daniela Abramovitz, Erika  
Clairgue, Arnulfo Bañuelos, Thomas Patterson,  
Steffanie Strathdee, and Leo Beletsky*

- 239 The Impact of the Presidential Alternative  
Treatment Program on People Living with  
HIV and the Gambian HIV Response  
*Sarah L. Bosha, Michelle Adeniyi, Jenna Ivan,  
Roya Ghiaseddin, Fabakary Minteh, Lamin F.  
Barrow, and Rex Kuye*

- 253 Two Row Wampum, Human Rights, and the  
Elimination of Tuberculosis from High-  
Incidence Indigenous Communities  
*Richard Long, Courtney Heffernan, Melissa  
Cardinal-Grant, Amber Lynn, Lori Sparling,  
Dorilda Piche, Mara Nokohoo, and Diane  
Janvier*

## RESEARCH PROTOCOL

- 267 Assessing a Human Rights-Based Approach  
to HIV in Kenya  
*Neiloy R. Sircar, Tabitha G. Saoyo, and Allan  
A. Maleche*

## BOOK REVIEWS

- 283 Assessing Human Rights in Global Health  
Governance  
*Julie Hannah*
- 287 Being Bold about Rights in a Neoliberal  
World  
*Audrey Chapman*

## EDITORIAL

# Global Health Fieldwork Ethics: Mapping the Challenges

RACHEL HALL-CLIFFORD, DAVID G. ADDISS, ROBERT COOK-DEEGAN, AND JAMES V. LAVERY

## Introduction

As Paul Farmer has observed, “global health remains a collection of problems rather than a discipline.” An exclusive focus on technical problems and the quest for solutions obscures how global health is actually enacted and implemented through fieldwork. In this special section, we consider “fieldwork” broadly to include any on-the-ground research or program design, implementation, or evaluation conducted by or with local participants and communities, which often involves collaborators from abroad.

At the very heart of global health fieldwork, relationships—real-world connections among people and across institutions—give meaning to the goals and projects of this multidisciplinary field. Those relationships inspire us and compel us to act to reduce health inequalities and promote health and social justice. Yet, in working toward these goals, we must more fully consider the asymmetries embedded in global health practice—imbalances of power, access to resources, and decision making—many of which come to a head in the context of fieldwork.

The dynamics of global health fieldwork and the nature of the relationships that emerge through it have been conspicuously underexplored in global health scholarship. This special section of *Health and Human Rights Journal* highlights the ways in which participants interact and *experience* the work of global health. It is an effort to shed light on some of the ethical challenges of fieldwork and to explore terrain that might lead to practical ethical guidance for global health fieldworkers.

Research regulations and traditional research ethics fall short in helping navigate many of the challenges that arise in global health practice. The US Federal Policy for the Protection of Human Subjects,

---

RACHEL HALL-CLIFFORD, MPH, MSc, PhD, is an associate professor of anthropology and public health at Agnes Scott College in Georgia, USA, and director of the National Association for the Practice of Anthropology – Occupational Therapy Field School in Guatemala.

DAVID G. ADDISS, MD, MPH, is director of the Focus Area for Compassion and Ethics at the Task Force for Global Health in Decatur, USA.

ROBERT COOK-DEEGAN, MD, is a professor at the School for the Future of Innovation in Society, and at the Consortium for Science, Policy and Outcomes at Arizona State University, USA.

JAMES V. LAVERY, PhD, is Conrad N. Hilton Chair in Global Health Ethics and a professor in the Hubert Department of Global Health, Rollins School of Public Health, and Center for Ethics at Emory University in Atlanta, USA.

Please address correspondence to Rachel Hall-Clifford. Email: rhallclifford@agnesscott.edu.

Competing interests: None declared.

Copyright © 2019 Hall-Clifford, Addiss, Cook-Deegan, and Lavery. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

first adopted in 1991 and known as the Common Rule, establishes procedures and regulations for research involving human participants and builds on the 1979 Belmont Report ethical principles of respect for persons, beneficence, and justice.<sup>2</sup> Most of the ethical issues raised in this special section fall outside the scope of the Common Rule, which has become the de facto international standard, due in part to the power and reach of US federal funding. The dominance of the Common Rule paradigm allows for adherence to procedural ethics without attending to many broader ethical questions that emerge from global health fieldwork, such as guidance on financing, “ownership” of programs and appropriate engagement with stakeholders, and, increasingly, data sharing and the implications of big data. Moreover, there is very little emphasis on institutional or organizational ethics in global health research, which belies the centrality of interpersonal and institutional relationships that are at the heart of the global health enterprise. These relationships are shaped by inherent power imbalances between high-income and low- to middle-income countries that are not fully acknowledged for their deep influences on how we think, work, and evaluate success in global health. Yet it is precisely through these relationships that the relevance and value of the right to health becomes tangible.

As a multidisciplinary field, global health does not have clear or consistent guidance for fieldwork ethics. Perhaps our unshakable belief in our shared mission to improve health and the lives of marginalized populations across the globe has made us too complacent about the ethical stakes involved in the complex interpersonal and institutional relationships that fuel all global health efforts. This has significant implications for human rights—the very ideals we seek to promote—since it has allowed breaches of ethics, inadvertent or otherwise, to go underreported and under-examined. Local collaborators, project communities, and fieldworkers themselves are made vulnerable by the gap between procedural ethics and the complex ethical realities of fieldwork in global health.

## Workshop on Ethically Managing Global Health Fieldwork Risks

In April 2018, a group of 29 global health researchers and practitioners from various disciplines, institutions, and career phases—from students to CEOs—came together for the Workshop on Ethically Managing Global Health Fieldwork Risks held at Agnes Scott College in Decatur, Georgia, USA. The idea for the workshop initially emerged through informal, serendipitous conversations. Each of us has worked in global health, and we have experienced situations in the field that led us to question our own actions and to seek ethical guidance, which was largely absent from the global health literature (see Hall-Clifford and Cook-Deegan; Addiss and Amon; and Graham, Lavery, and Cook-Deegan in this issue). We came to realize that our varied experiences spoke to shared encounters with the gap between ethical principles and the complexities of real-world fieldwork.

The primary objective of the two-day workshop was to provide a place to consider fieldwork experiences and ethical challenges. The format involved each participant sharing a short case example from their own work that presented particular ethical questions, followed by discussion. Through creating opportunity for dialogue, we wanted to begin mapping the fieldwork challenges that participants had experienced. While we recognized that an exhaustive taxonomy of every ethical challenge and situation that global health fieldworkers face may not be possible, we wanted to do more than throw our hands up in despair at the complexity.

What emerged during the workshop was a rare opportunity to share fieldwork experiences, including mistakes and vulnerabilities, across disciplinary and researcher-practitioner boundaries. Topics covered by participants’ case examples included power dynamics within global health funding and agenda setting; inequalities among foreign and local global health staff; the limits of consent, participant recruitment, data security, and resource allocation in contexts of crisis; challenges in training and supporting global health students;

issues in global health photography and communication; personal and moral injury to global health fieldworkers; gender-based violence in the field; and organizational and institutional roles in ensuring ethical practices. Although far from exhaustive, these workshop topics suggest a preliminary taxonomy of ethical issues that have largely evaded serious attention in the traditional global health ethics guidance documents.

Many of the discussions also signaled broader ethical challenges within the paradigms through which we conceptualize and conduct global health fieldwork, such as the common practice of having foreign fieldworkers parachute in for short periods of time and expectations of ethical on-the-fly decision making. Another theme centered on the challenges and shortcomings of our efforts to provide adequate preparation for students to participate in fieldwork, particularly in light of the increased pressure on universities to compete for students by offering meaningful work experiences early in training programs. The expectation that students should engage in the field early coupled with the dearth of cohesive practical ethics in global health can lead to terrible outcomes for students—who are often left without appropriate support before, during, or after fieldwork—and their local hosts.

The most salient and pressing theme that arose from the workshop was gender-based violence in the context of fieldwork and the lack of open discussion about it in global health. Nearly every woman in the room had been touched by gender-based violence, and many of the men were shocked at how pervasive an issue this is for their colleagues. We explored the challenges that women fieldworkers and local participants face as well as the reality that global health workers can be the perpetrators as well as the victims of gender-based violence during fieldwork.

### In the special section

The articles in this special section, which emerged following the workshop, present a wide array of global health fieldwork ethics challenges, which

powerfully illustrate the ways in which global health has not adequately addressed on-the-ground ethics. Above all, the papers illustrate that unexpected situations and encounters frequently occur during fieldwork, often with problematic outcomes. Rachel Hall-Clifford and Robert Cook-Deegan highlight risks associated with fieldwork conducted in dangerous places and illustrate how failures to navigate those risks can lead to immense harm to community participants and fieldworkers themselves. David G. Addiss and Joseph J. Amon further explore unintended harms in global health and critically examine our individual and institutional responses to situations that call for apology and reparation.

Another key theme emerging from the contributions to this special section is the insufficiency of training for global health fieldworkers on the dangers and realities of fieldwork. Aimee Lorraine C. Capinpuyan and Red Thaddeus D. Miguel explore the challenges of participating as medical interns in a program to extend the reach of health services in the Philippines, and Jacob Roble et al. describe the efforts of a student-led group to improve preparation and accountability for undergraduate short-term global health experiences within the university context. Beyond their time as students, ongoing ethics training and support is vital but often absent for global health professionals. Izraelle McKinnon et al. describe the outcomes of human rights training for staff working in global health projects, highlighting a lack of clarity around how current training on ethics and human rights principles is acted on in the field. While we must support individual fieldworkers in making ethical decisions in the field throughout their careers, we must also further incorporate ethics into our institutional norms and protocols. In his commentary, David Ross describes efforts at the Task Force for Global Health to further institutionalize ethical thinking at every level.

Across global health, the representation of global health project participants and communities in publications and publicity can underscore the deep power dynamics embedded in the field. Au-

brey Graham et al. examine these power dynamics through the techniques and use of photography in global health fieldwork. Sharing data fairly and responsibly with participating communities presents further ethical challenges. Alyssa Mari Thurston et al. explore the lack of ethical guidance in communicating study results to participants and communities through an analysis of breastmilk biomonitoring studies, pointing out a dearth of meaningful engagement with these stakeholders to shape ethical norms of practice and guidelines. Jennifer Mootz et al. expand the discussion of ethical dissemination of results in their consideration of gender-based violence in conflict settings, in which they question the ways in which to best protect individual participants while disseminating data to communities and entities which might help alleviate violence.

Finally, while gender-based violence has been lifted up as a central concern for global health, particularly in relation to universal health coverage, its negative impact in global health fieldwork is inadequately recognized and remains largely unaddressed. There are key challenges both in how to ethically study and work to end gender-based violence and in how to support global health fieldworkers who experience it. Shana Swiss et al. further explore the ethical implications of gathering data on the impact of conflict on women. Arachu Castro describes her long-term work in documenting obstetric violence against women in Latin America and articulates some of the challenges of her dual roles as global health researcher and activist. Further elaborating on the theme of insufficient training, Corey McAuliffe et al. present data on the experiences of female graduate students in global health, including experiences of gender-based discrimination and violence. In her commentary, Rachel Hall-Clifford shares experiences of sexual harassment and assault during global health fieldwork, recognizing that such accounts are largely absent from the fieldwork literature and discussions within the field. Finally, the special section includes a joint statement against gender-based violence in global health fieldwork by many participants of the 2018 workshop. Global health must take action to

end this widespread but typically invisible violation of rights during fieldwork.

## Steps forward

The articles in this special section point to many perils—practical, ethical, and moral—in global health fieldwork. Yet we believe they also point to important points of entry to improve our ethical practices and to develop clear guidance and support for fieldworkers in global health. Across the field, efforts are underway to address our ethical shortfalls. Training is being improved by the sharing of lessons learned through collective groups, such as the Consortium of Universities for Global Health, and the opportunity for deep engagement with the experiences of fieldworkers, including through resources such as the Human Engagement Learning Platform for Global Health. Institutions are also moving toward broadening their scope of ethical responsibility, such as the Focus Area for Compassion and Ethics at the Task Force for Global Health, and organizing action to increase equity within global health, such as the work of Women in Global Health. These emerging projects and programs are hopeful signs that our unexamined bureaucratic processes and norms of practice are being disrupted in favor of a deeper ethical reckoning. As many of the articles in this special section illustrate, human rights violations—of local participants, project communities, and fieldworkers—occur within the context of global health fieldwork. It is our responsibility as a field, particularly one dedicated to the promotion of health as a human right, to establish clear and practical ethical guidance to mitigate and eliminate these violations and to ensure that the relationships we build are ones of partnership and equality.

## Acknowledgments

The authors thank Agnes Scott College, the Task Force for Global Health, and the Emory University Rollins School of Public Health for their co-sponsorship of the 2018 Workshop on Global Health Fieldwork Ethics. We extend particular gratitude



to Elizabeth Kiss, who as President of Agnes Scott College energetically supported this project and lent her expertise as an ethicist to the workshop. We also thank Arthur Kleinman, who delivered the 2018 Agnes Scott College O.C. Hubert Public Lecture, “Caregiving: What Distinguishes the Social Medicine Approach to Global Health,” as the inaugural workshop event and provided invaluable insight as a participant in the workshop.

## References

1. P. Farmer, “Preface,” in P. Farmer, J. Y. Kim, A. Kleinman, and M. Basilio (eds), *Reimagining global health: An introduction* (Berkeley: University of California Press, 2013).
2. US Department of Health and Human Services, Office for Human Research Protection, *Federal Policy for the Protection of Human Subjects (“Common Rule”)*. Available at <https://www.hhs.gov/ohrp/regulations-and-policy/regulations/common-rule/index.html>.



# Ethically Managing Risks in Global Health Fieldwork: Human Rights Ideals Confront Real World Challenges

RACHEL HALL-CLIFFORD AND ROBERT COOK-DEEGAN

## Abstract

Global health is an interdisciplinary field engaged with implementation of the human right to health, yet ethical dimensions of the on-the-ground realities of this work have been underexplored. Fieldwork in global health produces knowledge through both primary research and the lessons of practical program implementation. Much of this essential knowledge, which often documents health disparities and other human rights abuses, arises from work in dangerous contexts. Work in such environments entails risk to all participants in the global health enterprise, both local and foreign, but affects them differently. The risks of ethical fieldwork must be considered not only for the well-being of project participants and fieldworkers but also in light of how they shape and constrain global health research and program implementation. Drawing on case examples from the authors' fieldwork, this article marks an effort to begin disentangling the realities of risks in the field and the responsibility borne by the fieldworker to undertake ethical action, recognizing that decisions are often made without established protocols or the immediate availability of guidance from colleagues. We call for further engagement within global health on ethical issues distinctive to the complex and dangerous places in which the promise of a right to health is enacted in the real world.

---

RACHEL HALL-CLIFFORD, MPH, MSc, PhD, is an associate professor of anthropology and public health at Agnes Scott College in Georgia, USA, and director of the National Association for the Practice of Anthropology – Occupational Therapy Field School in Guatemala.

ROBERT COOK-DEEGAN, MD, is a professor at the School for the Future of Innovation in Society and at the Consortium for Science, Policy and Outcomes at Arizona State University, USA.

Please address correspondence to Rachel Hall-Clifford. Email: rhallclifford@agnesscott.edu.

Competing interests: None declared.

Copyright © 2019 Hall-Clifford and Cook-Deegan. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

## Introduction

*The cobblestones up the hill to “my” family’s house in a highland Guatemalan town always felt satisfying under my feet as I walked homeward in the late afternoons. Alternately warmed by the sun or slick with rain depending on the season, they led home, past friends and neighbors to be greeted along the way. I reveled in the feeling of belonging that marks accomplishment as a fieldworker. The physical exertion of the climb was gratifying after a day spent on the far less concrete efforts of interviewing, observing, and doing surveys about children’s access to primary health care services. The members of the family with whom I lived energized me, quickening my steps toward the warmth of the stove and evening conversations. They were indigenous, mobilized, and brilliant.*

*More than 20 years after the Guatemalan peace accords ended a decades-long genocidal civil war, rates of ethnic violence remain high. My adopted family was torn apart when an adult son was assassinated for being an activist. His body bore the testament that the indigenous must know their place—his tongue cut out, his brain bashed in as a visceral message to silence those who challenge the status quo. The family spent a frantic evening searching for him when it became apparent he had been taken, their feet flying over those same well-worn cobblestones. They found him clinging to life in a ditch at dawn; there was no time to save him, only to glimpse his incredible suffering and say inadequate goodbyes.*

*Following the assassination, I received a few anonymous threatening voicemails and stayed physically away, an option I was very aware of having but which the family did not. Years of grief and indecision followed. The family ultimately decided not to pursue prosecution of the murder in the face of futility and fear of reprisals. Beyond my sadness at the loss of my friend, I feel guilt, however misplaced or even self-aggrandizing, that my projects and shared passion for indigenous causes may have helped invite trouble. My beloved daily journey to their door, when reconsidered, becomes a pale flag marking with each wave an invitation to deadly scrutiny.*

Though an extreme example, this fieldwork experience of the first author illustrates that well-intentioned and carefully implemented fieldwork can

expose local partners, participating communities, and fieldworkers themselves to unforeseen and disastrous outcomes. Fieldwork in global health, rooted in the advancement of health as a human right, is intended to produce knowledge through both primary research and the empirical lessons learned through program implementation. Much of this knowledge—whether illustrating health disparities, documenting abuses committed against people, or describing factors that undermine the capabilities needed to lead a fully realized human life—is gained by gathering data in dangerous places. This work entails risk to global health fieldworkers and to those around them. Those risks are often confronted with little or no training, based on an implicit assumption that dangers can be successfully and ethically navigated by the fieldworker. Failures to do so have no formal place in reporting global health project outcomes, and community participants and fieldworkers can be left to grapple with the aftermath without systematic support. Beyond an unfulfilled responsibility for the well-being of fieldworkers and project collaborators and communities, global health must also account for the ways in which the knowledge that informs goal setting and principles of practice is shaped by the risks and ethical challenges of fieldwork.

An exhaustive taxonomy of the practical and ethical challenges of fieldwork is infeasible, given the wildly diverse situations in which global health and human rights workers may find themselves. Yet anticipating potential risks to fieldworkers and their project communities can help mitigate them. Risks faced by fieldworkers arise through the possibility of causing harm to others and the possibility of harm to fieldworkers themselves. Firsthand accounts of fieldwork challenges have begun to emerge in the literature.<sup>1</sup> In this article, we share examples from our own work in an effort to illustrate some of the gaps between ethical ideals and realities in the field. We focus on the experiences of fieldworkers in navigating the appropriate level of engagement and activism in project communities, implementation of informed consent in contexts of crisis, routine dangers in the field, and grappling with self-identity and morals in the field. We propose a global

health ethics practice framework to systematically (1) anticipate the ethical issues likely to arise in fieldwork, (2) incorporate practical fieldwork skills and applied ethics into global health training, and (3) share ethics-related lessons learned from fieldwork in professional publications and discourse. This practice framework can help bridge the gap between particular field experiences and the abstract principles of research ethics through a focus on applications to real world contexts.

## Background

### *Global health evidence and ethics*

Global health is an interdisciplinary field drawing from academic disciplines across human rights, medicine, and the natural and social sciences. Perhaps due to this interdisciplinarity, global health has not settled on a coherent, cross-cutting set of theories to produce evidence through a formal inductive process as in other academic disciplines.<sup>2</sup> From another interdisciplinary approach, human rights has grown from its roots in activism and law to include direct empirical observation, which often entails engagement with people who have been abused or are close to those who have been. Yet global health and human rights have both adopted forms of validating and disseminating data from the natural sciences. Standardized methods-results-conclusions publication formats often leave little place for the disclosure of fieldwork or implementation realities that muddle interpretations of the data presented. The data then form the evidence base for programmatic decisions and principles of practice.

Gaining valid data in contexts where security is uncertain and human rights are not respected is challenging.<sup>3</sup> Discussions of global health fieldwork ethics tend to be abstract and separate from the reporting of results from particular projects. Most publications describe methods with little or no attention to the risks and challenges faced by fieldworkers or those with whom they work. This omission may be appropriate when conditions do not intrude on the fieldwork, but challenges should be explicitly addressed when the context limits the gathering of data, when methods taken to mitigate

risks might influence outcomes, or when experiences might be used to educate future fieldworkers. Important emphasis has been made in recent years on the dissemination of research findings within project communities, though important questions about how to do so safely and ethically remain (see Mootz et al. in this issue).

Public health ethics tend toward the teleological, even utilitarian, as we attend to maximizing good and minimizing harm for populations as a collective.<sup>4</sup> This tendency seems also to have shaped approaches to fieldwork, with vital, life-saving ends sometimes justifying less-than-ideal means when it comes to research and implementation in dangerous contexts. By nature, global health and human rights empiricism must cross geopolitical and cultural boundaries.<sup>5</sup> Global health also confronts sociocultural differences and substantial power imbalances between fieldworkers and community participants.<sup>6</sup> Significant work in the past two decades has been dedicated to improving methods of community participatory involvement in global health programs and establishing meaningful community engagement.<sup>7</sup> Yet many of the risks in global health fieldwork continue to be borne by particular individuals or groups who may have little input in goal setting and study design of the global health programs that may put them at risk.<sup>8</sup> Reckoning the costs and benefits of global health interventions in resource-constrained settings undoubtedly varies among individual, community, state, and international perspectives.<sup>9</sup> Advancement of health as a human right, the principles of partnership, and the promotion of justice become even more challenging when we consider the uneven distribution of the risks of harm from global health programming.<sup>10</sup> Confining attention to procedural ethics by meeting US Common Rule standards for informed consent, reciprocity, confidentiality, and conflicts of interest from funding sources limits consideration of the broader implications of the political and economic structures in which global health research takes place.<sup>11</sup>

### *Critical humanitarianism and the right to health*

Though its programs are often framed as political-

ly and morally neutral, global health is rooted in globalized notions of humanitarianism to enact the right to health.<sup>12</sup> While global health focuses on making the right to health a reality via affordability, accessibility, availability, and quality, this mission is underpinned by the values of a dominant neoliberal geopolitical system.<sup>13</sup> Responsibility for respecting, promoting, and fulfilling rights falls to states, leaving uncertainty about the extent of moral obligations across political jurisdictions.<sup>14</sup> Peter Van Arsdale and Derrin Smith articulate three key principles of modern humanitarianism: benevolence, autonomy, and nonmaleficence, which resonate with our traditional notions of research ethics, but they caution that there has been no consensus among humanitarian fields of practice about how these ethical principles can be enacted.<sup>15</sup>

Relationships in global health are inherently asymmetrical due to the power differentials between the actors and institutions who are most often in positions of responsibility for setting and directing global health strategies and those who are positioned as recipients of their strategies.<sup>16</sup> Global health programs and the human rights abuses they seek to remedy occur at both the local and global levels.<sup>17</sup> Fieldworkers confront the entanglement of politics and compassion—the competing motivations embedded within relationships of giving—on the front lines of this intersection.<sup>18</sup> Human solidarity has been positioned as a core principle for overcoming the inevitable inequalities of power and wealth inherent in interpersonal engagement in global health.<sup>19</sup> However, questions remain about how such solidarity might be enacted in the field. It can obscure the motivations for global health interventions and for the engagement of individual fieldworkers with project objectives. Particular acts of solidarity may create greater risk for local project partners and fieldworkers, as in the opening example in this article. Given the complex and at times problematic nature of humanitarianism in creating sustainable improvements rooted in respect and mutuality, the challenges—moral, ethical, and practical—facing the individual fieldworker or project team on the ground are immense.

## Methods

Our analysis draws on our experiences as fieldworkers in global health research, program implementation, and advocacy. Hall-Clifford has worked in Guatemala as a medical anthropologist and global health practitioner for nearly 15 years and has also contributed as a research scientist and consultant to projects in Africa and Eastern Europe. Cook-Deegan did medical humanitarian work in Central and South America early in his career, and then confronted ethical dilemmas again when on human rights missions to Central America, Turkey, and Iraq and through human rights advocacy at the national and international level. While we draw on our own particular experiences in the field via brief examples in order to illustrate our ideas for developing a practical fieldwork ethics framework, we believe these experiences resonate with those of others shared in the emergent literature and with the lived experiences of colleagues in the field.

## Harm to others and responsible (in)action

### *Unintended harms*

Global health is littered with examples of research projects and program strategies that had unintended outcomes, both good and bad.<sup>20</sup> The good includes durable health delivery systems and community engagement, and the bad includes worsening the burden of disease, environmental calamity, and unforeseen sociopolitical consequences. Fieldwork has been a critical part of the burgeoning evidence base in global health and underpins its intervention design theory. Here, however, we concern ourselves with the sometimes dire, but often unacknowledged, consequences of interpersonal engagement of the fieldworker within communities and the attendant realities of research and project implementation. Clearly not all global health fieldworkers are outsiders to the communities in which they work. Often, marked inequalities of visibility and agency exist between foreign and national fieldworkers, and the two sets of actors may face very different dangers in field settings.<sup>21</sup> National fieldworkers and community



implementation teams are set apart and potentially made vulnerable by virtue of their involvement with projects connected via intellectual ancestry or funding to the broader, external global health or human rights polity.<sup>22</sup>

As described in the introduction, the Guatemalan field experience of the first author included unequivocal, irreversible harm for which she had little preparation or institutional support. The inescapable fact is that harm can come to community members through engagement with global health projects and their fieldworkers. In this case, the fieldworker was neither directly responsible for the violence directed at her friend and colleague nor even the source of his initial community-based programming and advocacy work. However, the excitement of sharing ideas and work was mutually encouraging but may also have led to risk taking that resulted in death. Moreover, the simple act of being seen working with a foreign researcher may have drawn the attention of the perpetrators. The sister of the person murdered told of the horror of that death and its repercussions:

*[He] only ever worked for human rights; visiting communities, helping [people] know their rights. He did nothing wrong ... Almost everyone [in town] knows who did it, but they can't find witnesses. No one wants to testify, and how would the family feel if someone did and something happened? They didn't just kill him, they tortured him. He was screaming. My mom didn't want to live, couldn't get out of bed.*<sup>23</sup>

There was unfathomable loss to be borne by the family as they grappled with how to reengage with a terrifying new reality so at odds with all they had worked for in creating indigenous solidarity and the heartbreaking practicalities of supporting the deceased's young child and pregnant widow. The indigenous community experienced a fresh cycle of suspicion and fear that was all too familiar from the days of the civil war, and community health and development projects were unsurprisingly hampered. The family eventually decided not to pursue prosecution of the assassination, feeling that it was futile, potentially too costly, and risky. His sister said a few years afterward, "Now we can have peace

because we have let it go. It wasn't good to have so much hate. My mother would see them [the perpetrators] in the street and want to kill them. It wasn't good to have so much hate inside."<sup>24</sup> She took comfort in the idea of divine justice.

For the global health fieldworker in this instance, divine justice seemed a poor salve for such terrible mutilation of this well-loved family. Following the death, a flurry of calls and emails to lawyers and human rights organizations explored options and contemplated prosecutorial justice. It took years to recognize that these actions, while done in concert with the family, were not fulfilling their needs but rather those of the fieldworker to be active, to avenge, and even to expiate guilt. All of these experiences were well outside the preparation for fieldwork, despite training in social theory, research ethics, and protocols approved by institutional review boards. Conventional research ethics fell far short of preparing for, much less averting, a very real and tangible moral catastrophe, and the episode was not reported as part of the fieldwork, though some similar experiences were shared by an academic advisor working in the same region 30 years earlier.<sup>25</sup> We surmise that bad things often happen during fieldwork that remain unreported, with unclear channels and few outlets to do so. A coherent global health ethics practice framework should include explicit attention to potential risks, training in anticipating and mitigating such risks, and reporting of field experiences alongside data.

#### *Limitations of traditional research ethics*

Further limitations of research ethics in the field are illustrated by two examples drawn from a human rights mission to Southeast Turkey in the weeks after poison gas attacks against the Kurds of northern Iraq in 1988.

*A team of fieldworkers from Physicians for Human Rights came in October 1988, prepared with cameras and surveys to document the poison gas exposures that occurred in August, ten weeks before. The survey, translated into Kurdish, was based on a questionnaire designed years earlier by Canadian experts for the World Health Organization to elicit information about poison gas exposure. Interviews with those from northern Iraq, now housed in*

*refugee camps in southeast Turkey, did indeed yield evidence of exposure to mustard gas.<sup>26</sup> But while this provided information that was valuable at a time when there was little objective and credible evidence about the use of poison gas, the work included two mistakes. One was a failure to protect the camp residents who were interviewed in the camps—we published a photograph taken in a refugee camp that could be used to identify those who had spoken to us. We told residents we might use photographs and the survey information in publications, but they could not have foreseen that authorities might also use our own information to identify those who had helped us. To our knowledge, this did not occur, and we do know the whereabouts of those most likely to be targeted. Yet we also know that authorities were acquainted with our work, because an Iraqi expatriate journalist returned from London to northern Iraq and was executed; he had our report in his possession at the time he was arrested.*

The other mistake was tactical but illustrates the ambiguous moral architecture of fieldwork in contexts where human rights are routinely violated.

*After a first set of interviews and surveys in a refugee camp near Mardin, southeastern Turkey, the team was summoned to meet with the regional governor, who at the time had dictatorial powers because a five-state area was under martial law. He was an overt racist who spoke openly about Kurds as “dirty animals who live in caves,” and he had presided over grotesque atrocities. Amnesty International had reported the torture—and sometimes death—of detainees in a prison just a few blocks from where our interview took place in Diyarbakir.*

*When asked what we were doing in the region, as team leader, the second author of this paper noted that we were American doctors who wanted to assess the health of those who had been attacked in northern Iraq and were now in camps in southeastern Turkey. When I mentioned the use of a survey, the energy in the room suddenly changed, from superficial joviality to sudden awareness that our work was a real threat to the political interests of the regional governor. We were never granted access to another camp, and our rooms were broken into and my briefcase opened (and its contents presumably photographed). We had, however, deliberately left the briefcase with a few blank survey forms in the room, hiding the completed surveys, videotapes, and photographs on our bodies, and we*

*also left some documentary material with a trusted colleague to independently ship back to us.*

This mistake was entirely avoidable. Volunteering information about the use of a survey instrument was gratuitous in the moment of our interview with the regional governor. The failure to fully explain our methods would have indeed been taken by the authorities to be a deliberate withholding of pertinent information, but given the political context, revealing such details was a blunder that undermined the primary purpose of the human rights mission. The second author learned from this mistake, but the only others who also learned were members of the team and the Physicians for Human Rights staff who were immediately made aware of it by phone after the meeting was over.

This one mission thus entailed unnecessarily putting refugees at risk of identification in a region where human rights were notoriously violated, and gratuitously volunteering information that undermined the process of documenting poison gas attacks. Forethought and common sense could have avoided both mistakes. Training—and perhaps more regular sleep—would have made such forethought more likely, and might have avoided problems from occurring in the first place. In some respects, the digital data storage tools now available can reduce opportunities for breaches of confidentiality of physical data, but they introduce new vulnerabilities for keeping data secure and ways that field findings can be misused.

### *Enacting ethics*

The two fieldwork examples described above highlight the troubling inability of traditional research ethics to offer adequate safeguards to local participants in global health projects. As the fieldworkers involved, we can unequivocally say that we undertook our projects with clear, ethics-approved protocols and also hold a deep commitment to ethical practice as fieldworkers. Even so, these experiences give us pause—not just in terms of how we responded in the field, but also as cautionary tales about the need for training to address ethical dilemmas likely to arise in fieldwork. The gaps in



established norms and practical ethics relevant for global health have real consequences for our communities of research and practice. It is the murky interstitial spaces between clear-cut implementation of project protocols and the human realities of being in the field, often in unstable or violent contexts, that most concern us.

At the root of the many conundrums facing fieldworkers in navigating the practical ethics of global health fieldwork is the double bind of acting responsibly by avoiding doing either too much or too little. In the first case from Guatemala, the friend and colleague was not killed directly as a result of his engagement with the global health research project, but the presence of a foreign fieldworker drew attention to him and the family household. In retrospect, what seemed like encouragement of a friend and potentially useful community engagement was dangerous and pushed beyond the boundaries of acceptable activism for the place and time. Perhaps in such encouragement, the values of the fieldworker (and the broader agenda of social justice promoted by global health) took primacy over local realities. Here, the fieldworker likely did too much, going beyond the scope of an original project to encourage and support community activism.

In the second example, regarding Iraqi refugee camps, the fieldworker did too little to implement research consent processes and protections of subjects on the one hand and over-explained the project to local authorities on the other, undermining the very purpose of the fieldwork. Others considering fieldwork ethics have also contended that informed consent processes cannot appropriately be applied in situations where rights are being violated.<sup>27</sup> Consider the interview with the regional governor in southeast Turkey described above. Was that interview with a human subject of research? Should that interview be governed by fully informed consent? Clearly not, since the purpose of the mission was to gather information that the governor was committed to suppressing. When and how to apply the tenets of human research protections in complex political contexts warrants training and informed anticipation. Non-intervention in the face of human rights abuses is unethical,

but how appropriate action can best be undertaken and how such action can be adjudicated in the field are significant challenges.<sup>28</sup>

## Risks to fieldworkers

### *Dangers in the field*

Myriad risks confront global health fieldworkers. While some risks are the quotidian dangers faced by any relatively wealthy outsider to low-resource settings, others are specific to the nature of global health fieldwork. Challenges and risks are to be expected in undertaking work in politically unstable environments or conflict zones. Yet perhaps we prize the ability to navigate these challenges and risks as individuals too highly, above the development of cohesive norms of practice within global health. The ethos of fieldwork can embrace bravado and place trust in individual problem solving to navigate risky situations. The work of global health requires effective problem solvers in the field, but we should not allow fieldwork norms to be shaped by machismo or unconsidered risk. Fieldworkers by nature are perhaps drawn to adventure, decision making on the fly, or even the adrenaline rush of beating the odds of some particular risky barrier to the task at hand. Accounts of actions taken by fieldworkers in dangerous situations are typically shared only informally with colleagues, if shared at all, and have traditionally had little place in the global health literature. Such experiences are much more likely to be shared in the bar after conference proceedings than in the plenary.

In a promising development, accounts of fieldwork experiences and the “everyday violence” faced during them are increasingly being shared. The pressure to get results in dangerous and difficult circumstances can be intense, and the lines of what risks are appropriate become blurred.<sup>29</sup> While such risks are not unique to high-risk settings, they are much more likely where violence is common. A nascent literature on fieldwork acknowledges dangers to the fieldworker that are likely common in many of the resource-constrained and unstable loci of global health practice, such as robbery, sexual assault, gun violence, and warfare.<sup>30</sup> Even fewer pieces

in the literature on long-term fieldwork focus on or even include practical strategies for maintaining personal safety in dangerous settings.<sup>31</sup> How global health fieldworkers deal with threats to their safety seems to be understood as highly individualized, and the fear that such threats are likely to engender is largely unacknowledged. Singularly, Linda Green has described fear as a chronic condition endemic to her study communities in Guatemala, which limits movements and interactions for community members and the fieldworker.<sup>32</sup>

Our task becomes working from particular experiences toward shared principles. We cannot ignore the power and resource imbalances embedded within global health fieldwork. The threats to the first author in Guatemala, while frightening, felt vague and easily escaped in contrast to the ultimate consequence faced by her tortured and murdered local counterpart. The value of objectivity in bearing witness to suffering has limitations, and acknowledging shared pain or empathy helps us better understand the views, positions, and realities of local participants.<sup>33</sup> Grappling with and acknowledging fieldworkers' roles in research sites is vital to better understanding the realities from which our data emerge and disrupting the inequalities inherit within those relationships. Further, cultivating critical self-reflection—as individual fieldworkers and collectively—may assist global health in describing local realities in the context of global agendas, and may lend urgency to action against particular diseases and conditions, thus promoting humanitarian goals and supporting health as a human right.

### *The self in the field*

Doing the work of global health often places fieldworkers in unfamiliar locations. Adaptability to diverse and new environments is an essential quality for successful fieldworkers, and the perils faced by them are not limited to those resulting in the loss of property or physical harm. Fieldworkers frequently bear the weight of witnessing what they cannot change and the onus of this ineffectuality.

*In a very rural village where I conducted research in Guatemala, I listened each night as the three children*

*in the household where I lived cried themselves to sleep from hunger. The first night, tears stung my eyes and anger swelled in my chest as the children's mother yelled at them to shut up. I felt indescribable powerlessness that night and throughout my time in the village. I was one person with a small amount of grant money and could bring only a limited amount of food to the village—the most ineffectual of bandages. At the end of long days, hungry (but far from starving) from giving away my dinner, I would lie in my bed on the dirt floor and try to think of the bigger picture with ideas for possible improvements to rural health services, working to justify my meager offerings to this troubled place. All the same, I was repulsed when I eventually felt the words “shut up” rise to my own lips one night as the children cried incessantly in their hunger.*

The idea of local moral worlds—where the deeply embedded context of place and time situate the morality of actions—is compelling.<sup>34</sup> Particularly in long-term fieldwork in global health, the fieldworker may experience the dissonance of competing local moral worlds—those of the fieldsite(s) and those of the internal geographies of their own background. Satisfactory reconciliation of these two worlds can be elusive, rendering ethical responses to challenges and risks in the field difficult and marked by second-guessing. As Antonius Robben and Carolyn Nordstrom describe, “Existential shock is a highly personal and context-specific research phenomenon.”<sup>35</sup>

Reframing of one's sense of self, identity, and notions of morality as a result of field experiences can leave fieldworkers with unanswerable ethical questions, even regret.<sup>36</sup> What can or should have been done better? What culpability for poor outcomes from good-faith decisions made in the field, if any, do we bear? Is our presence in the field (with too much action or inaction) a waste of limited resources or, by extension, a collusion with structural violence and inequality? Liisa Malkki notes that those who undertake humanitarian work often do so because it makes them feel good or useful but are frequently left “feeling ambivalent, inadequate, and even impure about the work that they have done, despite their best efforts to fulfill the standards of their profession and their personal ethical commitments.”<sup>37</sup> Dangerous, unanticipated events in the

field can lead to post-traumatic stress disorder or other mental health concerns among fieldworkers, and few resources are allocated to these concerns within global health training programs and implementation organizations. There is often little support within the profession, either materially or interpersonally, to assist fieldworkers thus affected. The board of Physicians for Human Rights observed that those returning from missions frequently showed symptoms of post-traumatic stress disorder, exacerbated by sudden dissolution of the team that had an intense shared experience upon return. Is this a necessary condition of the work, or a feature to be recognized and addressed by anticipating it will occur and ensuring that the team remains in contact and has continued support? And what about fieldworkers who work alone? Making meaning from the lived experience of fieldwork should not be sidelined but rather integrated into our understandings of global health practice and the implementation science driving our work.

## Discussion

We acknowledge that the concerns and perhaps even the fieldwork case examples presented here may be dismissed as a move toward navel-gazing or shifting focus from the genuine work of global health and human rights, to privilege the experiences of fieldworkers over those of project communities. Undoubtedly, innumerable additional challenges in fieldwork ethics and safety confront fieldworkers beyond those drawn from our examples. Despite these limitations, we nonetheless contend that integrating explicit attention to ethical complexities of fieldwork into the discourse of global health as an interdisciplinary field is essential to improving it, understanding the evidence base, and equitably defining and advancing global health objectives. Collegial relationships often prioritize swapping “war stories” as a way to process and decompress from difficult fieldwork, with limited opportunities for systematically understanding how one’s experiences articulate with those of others in the field. Surely, field experiences should be personally processed with the support of family, friends, and

counsellors, but they must not simultaneously be divorced from our professional dialogue and reckonings of datasets. Rather, sharing stories of challenging fieldwork is a tool that can enhance practice in the field.

A global health ethics practice framework must be implemented to cohesively provide guidance on (1) the ethical issues likely to arise in global health fieldwork, (2) the practical fieldwork skills and applied ethics training needed by fieldworkers, and (3) the dissemination of ethics-related lessons learned from fieldwork within professional publications and discourse. The ethics challenges and risks facing both fieldworkers and project communities need to be explicitly recognized and addressed. An iterative ethics practice framework could do so by uniting ethical responsibilities with actual experiences in the field. As the examples in this article illustrate, fieldwork ethics must include workable strategies to safeguard communities that go beyond minimal adaptation of traditional research ethics for varied contexts, such as informed consent procedures, to a broader process through which core ethical principles can be made more concrete and relevant for local implementation. A global health fieldwork ethics practice framework would also create a foundation for building and sharing tools—examples of past problems, training materials, and open discourse on fieldwork realities—that would enable collective foresight in preparation for fieldwork.

Training in both traditional bioethics and engagement with practical ethical issues raised by global health fieldwork must be a part of the training of everyone engaged in global health—practitioners, academicians, and consultants. The establishment of global health ethics networks and training centers based in low- and middle-income countries could go a long way toward embedding ethics training and support for fieldworkers into research contexts.<sup>38</sup> Supporting capacity building for local institutional review boards in low- and middle-income countries to enable relevant, responsive, and fair review of research as well as community-based participation in research and program goal setting could also help.<sup>39</sup> As an interdisciplinary

field of practice, global health must perhaps work harder than other traditional academic disciplines to understand the norms of its diverse contributing disciplines and create shared ethical guidelines that can be used in the sometimes dangerous contexts of fieldwork. Perhaps most importantly, more articles that include explicit attention to the ethical issues that arise in fieldwork, more use of case examples, and explicit attention to the issues in training for fieldwork can all contribute to a more robust framework ethical conduct of fieldwork. Knowledge, the evidence base, arises from the successes and failures of research, program implementation, and documentation. We must more readily acknowledge the human element of this work.

Training programs in global health must include more intentional training on common fieldwork risks and strategies for how to avoid them (for example, carry a decoy wallet for robbers, barricade the door of insecure sleeping quarters with a rubber door wedge, etc.). This received wisdom is potentially as valuable as traditional field methods. Global health ethics training must take advantage of the opportunity to link global health research and practice to notions of justice and to critically discuss what this may mean in field contexts.<sup>40</sup> Strategies for mitigating risks for fieldwork participants should be more widely shared and adapted to local contexts. For example, the first author should not have been such a visible presence in the local indigenous activist community in Guatemala given the undercurrents of ethnic violence in the region. Meetings to understand and support health as a human right in this area should have been discreet and locally driven. Fieldwork training must also grapple with the more elusive questions of positioning of the self while in the field and afterward, and how to navigate engagements with local moral worlds that may clash with one's own. Ultimately, fieldworkers must strike a balance of doing neither too much nor too little while embedded in project communities. Engagement with a practical ethical framework can help individual fieldworkers and the field of global health become more confident that in-the-moment decisions in the field are ethical ones that minimize risks.

Finally, we must create space for routinely reporting fieldwork ethics issues in a way that goes beyond the procedural or punitive. Publications and presentations of global health work should be expected to include the dynamics and challenges of the fieldwork that produced the data or program outcomes being reported. The important shift in global health toward increased rigor in process evaluation and the turn in human rights to medical and scientific empiricism can serve as vital points of entry for explicitly including fieldwork realities in project reports. By doing so, we can bridge the current gap between fieldwork experiences and outcomes, good and bad, and the ethical principles and goals of promoting the right to health that underpin contemporary global health. The social sciences have well-developed methods for incorporating useful fieldworker self-reflection alongside qualitative data that could be profitably incorporated into the publication of global health projects.<sup>41</sup> Regular reporting and discussion of fieldwork experiences alongside the traditional scientific data would enable an ongoing inductive process to map fieldwork challenges and share strategies for managing fieldwork risks.

## Conclusion

Unintended, sometimes terrible, consequences can come from global health fieldwork or documenting human rights abuse. These consequences can affect individual local collaborators, project communities, fieldworkers, and the humanitarian programs and institutions that global health seeks to advance. Global health and human rights as empirical undertakings must more fully acknowledge the risks and dangers brought by fieldwork, the unequal experiences of these risks that local partners and foreigners may face, and the ways in which fieldwork realities shape documentation, research, and project implementation. With this article, we aim to open a conversation through which the field experiences of others in challenging or risky places can be discussed and meaningfully analyzed. Implementation of a global health ethics practice framework would institutionalize explicit attention



to considering fieldwork ethics, providing training on fieldwork risks and sharing ethical challenges arising from fieldwork. The framework should be centered on our dual responsibility to understand and prevent the risks to project participants and fieldworkers. This framework would be useful in training and supporting fieldworkers and the communities in which they work, drawing together the diverse disciplinary fields that contribute to the work of global health and the advancement of access to health care as a human right. Through an ongoing and iterative process of applying the ethics practice framework, the interdisciplinary endeavor of global health can build an experiential evidence base for the types of fieldwork challenges encountered and create best practices for managing fieldwork risks.

## Acknowledgments

The first author thanks Jonathan Maupin, Peter Rohloff, Martha Rees, and Chris DePree for input on the development of this article. The second author thanks Asfandiar Shukri, Howard Hu, and colleagues at Physicians for Human Rights for verifying the current safety of the refugees visited in 1988 and their feedback on the ideas in this article.

## References

1. S. M. Holmes, "Is it worth risking your life? Ethnography, risk and death on the US-Mexico border," *Social Science and Medicine* 99 (2013), pp. 153-161; B. Rylko-Bauer, L. M. Whiteford, and P. Farmer, "Prologue: Coming to terms with global violence and health," in B. Rylko-Bauer, L. M. Whiteford, and P. Farmer (eds), *Global health in times of violence* (Santa Fe, NM: School for Advanced Research Press, 2009); S. L. Pigg, "On sitting and doing: Ethnography as action in global health," *Social Science and Medicine* 99 (2013), pp. 127-134.
2. A. Kleinman, "Four social theories for global health," *Lancet* 375/9725 (2010), pp. 1518-1519.
3. C. Beyrer and N. E. Kass, "Human rights, politics, and reviews of research ethics," *Lancet* 360 (2002), pp. 246-251.
4. J. F. Childress, R. R. Faden, R. D. Gaare, et al., "Public health ethics: Mapping the terrain," *Journal of Law, Medicine and Ethics* 30/2 (2002), pp. 170-178; N. E. Kass, "Public health ethics: From foundations and frameworks to justice and global public health," *Journal of Law, Medicine and Ethics* 32/2 (2004), pp. 232-242.
5. G. Stapleton, P. Schröder-Bäck, U. Laaser, et al., "Global health ethics: An introduction to prominent theories and relevant topics," *Global Health Action* 13/7 (2014).
6. Kass (see note 4).
7. L. M. Whiteford and C. Vindrola-Padros, *Community participatory involvement: A sustainable model for global public health* (Walnut Creek, CA: Left Coast Press, 2015); J. V. Lavery, P. O. Tinadana, T. W. Scott, et al., "Towards a framework for community engagement in global health research," *Trends in Parasitology* 26/6 (2010), pp. 279-283.
8. B. Pratt and A. A. Hyder, "Applying a global justice lens to health systems research ethics: An initial exploration," *Kennedy Institute of Ethics Journal* 25/1 (2015), pp. 35-66.
9. G. M. Lairumbi, M. Parker, R. Fitzpatrick, and M. C. English, "Ethics in practice: The state of the debate on promoting the social value of global health research in resource poor settings particularly Africa," *BMC Medical Ethics* 12/1 (2001), p. 22.
10. C. Myser, "Defining 'global health ethics': Offering a research agenda for more bioethics and multidisciplinary contributions-from the global south and beyond the health sciences-to enrich global health and global health ethics initiatives," *Journal of Bioethical Inquiry* 12/1 (2015).
11. P. Bourgois, "Confronting anthropological ethics: Ethnographic lessons from Central America," *Journal of Peace Research* 27/1 (1990), pp. 43-54.
12. P. Redfield, "The impossible problem of neutrality," in E. Bornstein and P. Redfield (eds), *Forces of compassion: Humanitarianism between ethics and politics* (Santa Fe, NM: School for Advanced Research Press, 2011), pp. 53-70; S. R. Benatar, "Global health and justice: Re-examining our values," *Bioethics* 27/6 (2013), pp. 297-304; E. Stover and H. Weinstein, "Health, human rights, and ethics," *Cambridge Quarterly of Healthcare Ethics* 10/3 (2001), pp. 335-335.
13. S. Keshavjee, *Blind spot: How neoliberalism infiltrated global health* (Oakland: University of California Press, 2014).
14. N. Daniels, *Just health: Meeting health needs fairly* (Cambridge: Cambridge University Press, 2007).
15. P. W. Van Arsdale and D. R. Smith, *Humanitarians in hostile territory: Expeditionary diplomacy and aid outside the Green Zone* (New York: Taylor and Francis, 2010).
16. D. Fassin, *Humanitarian reason: A moral history of the present* (Berkeley: University of California Press, 2011).
17. P. Farmer and N. Gastineau, "Rethinking health and human rights: Time for a paradigm shift," in M. Goodale (ed), *Human rights: An anthropological reader* (Oxford: John Wiley and Sons, 2009).
18. C. Han, "The difficulty of kindness: Boundaries, time, and the ordinary," in V. Das, M. D. Jackson, A. Kleinman, and B. Singh (eds), *The ground between: Anthropologists engage philosophy* (Durham, NC: Duke University Press, 2014).
19. M. R. Hunt, L. Schwartz, C. Sinding, and L. Elit,

- “The ethics of engaged presence: A framework for health professionals in humanitarian assistance and development work,” *Developing World Bioethics* 14/1 (2014), pp. 47–55; A. D. Pinto and R. E. Upshur, “Global health ethics for students,” *Developing World Bioethics* 9/1 (2009), pp. 1–10.
20. Kleinman (2010, see note 2).
21. P. Redfield, “The unbearable lightness of expats: Double binds of humanitarian mobility,” *Cultural Anthropology* 27/2 (2012), pp. 358–382.
22. C. McInnes, A. Kamradt-Scott, K. Lee, et al., “Framing global health: The governance challenge,” *Global Public Health* 7/Suppl 2 (2012).
23. R. Hall-Clifford, personal communication (2010).
24. Ibid.
25. H. K. Heggenhougen, “Planting ‘seeds of health’ in the fields of structural violence: The life and death of Francisco Curruchiche,” in B. Rylko-Bauer, L. M. Whiteford, and P. Farmer (eds), *Global health in times of violence* (Santa Fe, NM: School for Advanced Research, 2009), pp. 181–200.
26. Physicians for Human Rights, *Winds of death: Iraq’s use of poison gas against its Kurdish population* (1989). Available at <http://physiciansforhumanrights.org/library/reports/iraq-winds-of-death-poison-gas-kurds-1989.html>.
27. P. Spicker, “Research without consent,” *Social Research Update* 51 (2007), pp. 1–4.
28. Bourgois (see note 11); Rylko-Bauer et al. (see note 1).
29. Holmes (see note 1).
30. A. C. G. M. Robben, and C. Nordstrom, “The anthropology and ethnography of violence and sociopolitical conflict,” in A. C. G. M. Robben and C. Nordstrom (eds), *Fieldwork under fire: Contemporary studies of violence and survival* (Berkeley: University of California Press, 1995), pp. 1–21; C. W. Watson (ed), *Being there: Fieldwork in anthropology* (London: Pluto Press, 1999); N. Scheper-Hughes and P. I. Bourgois, “Introduction: Making sense of violence,” in *Violence in war and peace* (Oxford: Blackwell, 2004); A. McLean and A. Leibing (eds), *The shadow side of fieldwork: Exploring the blurred borders between ethnography and life* (Oxford: Blackwell, 2007).
31. T. Williams, E. Dunlap, B. D. Johnson, and A. Hamid, “Personal safety in dangerous places,” *Journal of Contemporary Ethnography* 21/3 (1992), pp. 343–374.
32. L. Green, “Living in a state of fear,” in A. C. G. M. Robben and C. Nordstrom (eds), *Fieldwork under fire: Contemporary studies of violence and survival* (Berkeley: University of California Press, 1995), pp. 105–128.
33. R. Chierici, “Falling into fieldwork: Lessons from a desperate search for survival,” in A. McLean, and A. Leibing (eds), *The shadow side of fieldwork: Exploring the blurred borders between ethnography and life* (Oxford: Blackwell, 2007), pp. 204–218.
34. A. Kleinman, *What really matters: Living a moral life amidst uncertainty and danger* (Oxford: Oxford University Press, 2006).
35. Robben and Nordstrom (see note 30), p. 13.
36. C. Simon and M. Mosavel, “Getting personal: Ethics and identity in global health research,” *Developing World Bioethics* 11/2 (2011), pp. 82–92.
37. L. H. Malkki, *The need to help: The domestic arts of international humanitarianism* (Durham, NC: Duke University Press, 2015), p. 53.
38. P. A. Singer and S. R. Benatar, “Beyond Helsinki: A vision for global health ethics,” *British Medical Journal* 322/7289 (2001), p. 747.
39. L. London, “Ethical oversight of public health research: Can rules and IRBs make a difference in developing countries?” *American Journal of Public Health* 92/7 (2002), pp. 1079–1084.
40. M. R. Hunt and B. Godard, “Beyond procedural ethics: Foregrounding questions of justice in global health research ethics training for students,” *Global Public Health* 8/6 (2013), pp. 713–724.
41. J. Borneman and A. Hammoudi, *Being there: The fieldwork encounter and the making of truth* (Berkeley: University of California Press, 2009); A. P. Collins and A. Gallinat (eds), *The ethnographic self as resource: Writing memory and experience into ethnography* (New York: Berghahn Books, 2013); R. Behar, *The vulnerable observer: Anthropology that breaks your heart* (Boston: Beacon Press, 2014).

# Apology and Unintended Harm in Global Health

DAVID G. ADDISS AND JOSEPH J. AMON

## Abstract

Over the past few decades, investments in global health programs have contributed to massive advances in health for human populations. As with clinical medicine, however, global health interventions sometimes result in unintended harm, economic adversity, or social disruption. In clinical medicine, when medical error occurs, it is increasingly common for health care workers to offer apology, which involves acknowledging the error, taking responsibility for it, and expressing genuine remorse. In addition, hospitals are beginning to offer affected patients and their families reparation or compensation in an attempt to restore patients' health and repair relationships, as well as take steps to prevent similar harm in the future. By contrast, little is known about apology and reparation for unintentional harm in global health practice. Several factors, including the scale of global health programs, diffusion of responsibility across international networks of state and non-state actors, and concern that acknowledging harm could threaten otherwise successful health programs, render apology and reparation in global health more difficult than in clinical medicine. This article examines how and when individuals and global health organizations address inadvertent harm, illustrated by four case studies. It also describes ethical, legal, and human rights principles that could inform a more systematic approach. Addressing unintended harm in global health requires further attention at the individual, organizational, and global levels.

---

DAVID G. ADDISS, MD, MPH, is director of the Focus Area for Compassion and Ethics at the Task Force for Global Health, Decatur, USA.

JOSEPH J. AMON, PhD, MSPH, is director of global health and clinical professor at Dornsife School of Public Health, Drexel University, Philadelphia, USA.

Please address correspondence to David Addiss. Email: [daddiss@taskforce.org](mailto:daddiss@taskforce.org).

Competing interests: None declared.

Copyright © 2019 Addiss and Amon. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

## Introduction

Public health programs—conducted by local and national governments and global organizations—have contributed to massive advances in health for human populations, doubling the average life expectancy over the last century and reducing child mortality by nearly 90%.<sup>1</sup> Interventions such as large-scale vaccination campaigns, mass drug administration to treat and prevent neglected tropical diseases, vector control, improvements in water and sanitation, nutrition and fortification programs, and oral rehydration therapy have benefited millions of people in both high- and low-income settings.

Like clinical medicine, however, global health programs sometimes result in unintended harm. For example, stigma or serious adverse events can be associated with health promotion interventions or with programs administering vaccines or drugs to reduce the transmission of infectious diseases.<sup>2</sup> The history of global health provides several examples of well-intentioned interventions that, for a variety of reasons, resulted in unintentional injury, economic adversity, environmental harm, or social disruption.<sup>3</sup> The principle of *primum non nocere* (first, do no harm) remains an aspirational but often elusive goal in actual practice.<sup>4</sup>

A key ethical question for individuals and global health organizations is whether we acknowledge inadvertent harm when it occurs, and if so, how we respond to it. The field of global health ethics currently lacks a cohesive framework for navigating these and other ethical dilemmas. It draws on the values and principles of medical ethics and biomedical research ethics, which have developed robust (if not always adequate) approaches to reducing and addressing harm. However, the complexity and scope of global health render these frameworks insufficient. This article examines how and when individuals and global health organizations address inadvertent harm, illustrated by four case studies. It also describes ethical, legal, and human rights principles that could inform a more systematic approach.

## Responding to harm in clinical medicine and research

A landmark report in 2000 by the US Institute of Medicine, *To Err Is Human*, highlighted the unacceptable incidence and enormous cost of human error in medical settings.<sup>5</sup> Increasingly since then, medical professionals have been trained to offer apology, which involves acknowledging medical error, taking responsibility for it, and expressing genuine remorse to affected patients and their families.

But as ethicist Nancy Berlinger notes, to be effective, apology must be accompanied by “actions that materially restore the injured person to health, that repair the relational breach, and that safeguard against future injuries.”<sup>6</sup> With medical error, restitution—the restoration of what has been lost (in this case, health)—is often not possible. In its place, hospitals are increasingly offering some form of compensation or reparation, which, as Berlinger points out, is “always symbolic on some level, a repair of damage rather than a literal return of goods.”<sup>7</sup> Even in the absence of a verbal apology, reparation represents an acknowledgment of harm and an effort to take responsibility for it. Still, in many medical settings, apology and reparation are not offered effectively or well.<sup>8</sup>

Medical errors are rarely caused by the isolated actions of a single health care provider; systemic factors embedded within medical institutions also contribute. Power differentials between patients and health care providers and institutions contribute both to medical error and to reluctance to disclose it. For health care institutions, as for individual providers, disclosing and offering apology for medical error can be difficult. Barriers include fear of litigation, reputational risk, and concern for financial well-being.<sup>9</sup> However, where medical institutions have committed themselves to disclosing medical error and offering apology, they generally experience *fewer* lawsuits and *lower* costs of legal settlements.<sup>10</sup>

In biomedical research, egregious ethical lapses that result in harm to research subjects are often widely publicized. As in clinical medicine, these lapses are, to a large extent, the inevitable result of structural and functional differences in power



between investigators and research subjects. They also reflect a focus on ends over means, and the resulting acceptance of what Adriana Petryna calls “ethical variability” in conducting clinical trials. Ethical variability refers not to cultural relativism or legitimate differences in medical practice but to the exploitation of local factors such as poverty, lack of access to medical care, and substandard ethical review to efficiently recruit human subjects, resulting in “cost-effective variability in ethical standards in human research.”<sup>11</sup>

Two examples of ethical lapses in biomedical research involve studies of syphilis by the US Public Health Service. The infamous Tuskegee study, started in 1932, was intended to be a six-month long observational study of syphilis in black men. It ended only in 1972 after an Associated Press story led to widespread outcry.<sup>12</sup> The second study, also on syphilis, was conducted with sex workers, prisoners, and soldiers in Guatemala between 1946 and 1948.<sup>13</sup> Vulnerable persons in Guatemala were deliberately exposed to sexually transmitted infections without their consent. In both the Tuskegee and Guatemala studies, participants remained untreated long after effective treatment was available.

Revelations of ethical abuses in these and other trials provided an impetus for strengthened oversight of ethical review committees and international standards for conducting medical research. Increased funding was also provided to develop ethical review committees in low- and middle-income countries. Because of the high profile and seriousness of the abuses in Tuskegee and Guatemala, US political figures also offered apologies. President Clinton offered a public apology to the few remaining survivors of the Tuskegee study in 1997.<sup>14</sup> The apology was criticized by some as too little, too late.<sup>15</sup> A US\$10 million out-of-court settlement was reached with former study participants, and the US government promised to give lifetime medical benefits and burial services to all living participants (wives, widows, and offspring were subsequently added to the program).

In response to the Guatemala case, President Obama and Secretary of State Clinton apologized to Guatemalan officials in 2010.<sup>16</sup> The United States

increased financial support for the Guatemalan government’s sexually transmitted disease surveillance and control efforts and allocated funds for research ethics training in the country. While a lawsuit against the US government was dismissed, a suit against Johns Hopkins University, the Rockefeller Foundation, and Bristol Myers Squibb is ongoing.<sup>17</sup> The Office of Human Rights of the Archbishop of Guatemala filed a petition on behalf of victims with the Inter-American Commission on Human Rights in 2015.<sup>18</sup>

In response to the issues raised by these and other cases, new initiatives have been launched to bring attention to issues of fairness, ethics, and power dynamics in global health research.<sup>19</sup> However, proactive plans for compensation or apology in the case of harm during research studies are rarely discussed by researchers or ethical review boards. In addition, in some low- and middle-income countries, ethics committees have limited capacity or conflicting priorities, which can compromise their mission to protect individual research participants.<sup>20</sup>

### Responding to unintended harm in public health practice

Whereas ethical abuses in research settings present clear violations of research participants’ rights and call for accountability and reparations, unintended harm in public health *practice* presents a murkier case for understanding responsibility and appropriate responses. A recent review identified 26 articles published between 1992 and 2013 that described unintended harm in public health interventions.<sup>21</sup> The authors classified five specific types of harm: physical, psychosocial, economic, cultural, and environmental. Theo Lorenc and Kathryn Oliver, in a conceptual essay, provide a similar categorization.<sup>22</sup>

Even less examined than the documentation of unintended harm in the public health literature is the issue of when or how such harm is disclosed or addressed in practice, whether by individual health workers, organizations, or government leaders. In the highest-profile cases, public or political apologies for misguided or failed practices or omissions may occur. For example, the prime minister

of Japan apologized for discrimination against and poor treatment of persons with Hansen's disease, and the president of Liberia apologized for the government's failure to protect health workers from Ebola.<sup>23</sup> But how often do private apologies occur? What other steps are taken by global health practitioners or their institutions to apologize or implement approaches to restore relationships, such as some form of reparation, when breaches of trust occur between themselves and the intended "beneficiaries" of their programs? We examine these questions through four case scenarios from the field of neglected tropical diseases.

#### *Scenario 1: Potential harm through inaction*

On a hot August morning along a dusty road near Leogane, Haiti, a farmer approached me (DGA), holding his sick infant daughter in his arms. His eyes met mine as he pleaded for help. The little girl was suffering from severe diarrhea. As a physician, I could see that she needed urgent hospital care. But my role in Haiti was to help implement a lymphatic filariasis control program, not to work as a clinician. I felt ashamed as a physician: I knew what the girl needed but I was paralyzed by my own insecurities, my ignorance of the local health system, my lack of formal credentials to provide clinical care within that system, our pressing research schedule, and the social, structural, and economic inequities that separated us. Caught up with the research, which we hoped would someday benefit the entire population, we gave the man enough money to take his daughter to the hospital and went on our way. I never saw them again. I never returned to ask the man about his daughter.

#### *Scenario 2: Adverse event following mass drug administration*

Chris King, a physician and medical researcher from Case Western Reserve University, was working in a remote area of Papua New Guinea. He and his team were trying to stop the spread of lymphatic filariasis, a disabling and stigmatizing tropical disease that affects 120 million people worldwide. Their approach was to offer a single dose of medicine to the entire community, a strategy known as

mass drug administration. The project was going well until the team encountered strong resistance in one particular village. The reason, they learned, was that a woman in a neighboring village had suffered a miscarriage shortly after taking the medication. Word spread quickly and people were upset; they blamed the miscarriage on the medicine.

#### *Scenario 3: Serious adverse events causally associated with mass drug administration*

Soon after the discovery that ivermectin was safe and effective for onchocerciasis, also known as river blindness, Merck Inc. donated the drug free of charge to control this parasitic disease, which affected 25 million people, primarily in sub-Saharan Africa. Once-per-year treatment of all eligible members of at-risk communities provided massive relief from suffering; was associated with only mild, transient adverse reactions related to the death of the parasite; and had collateral benefits against other parasitic infections, such as intestinal worms and scabies.<sup>24</sup> It also advanced social justice.<sup>25</sup> The African Program for Onchocerciasis Control pioneered community-directed treatment in which communities made autonomous decisions regarding whether and when to participate, who would administer the tablets, and how community drug distributors would be compensated.<sup>26</sup>

This highly favorable benefit-risk balance shifted radically when a cluster of treatment-associated serious adverse events with neurologic complications was first reported, some of which were fatal. Initially, the cause was unclear, but investigations soon determined that these cases occurred in persons with high levels of infection with another, co-endemic parasite, *Loa loa* (also known as African eye worm).<sup>27</sup>

#### *Scenario 4: Iatrogenic transmission of hepatitis C*

Beginning in the 1950s and extending into the 1980s, the Egyptian Ministry of Health embarked on a community-wide treatment campaign for schistosomiasis, a debilitating parasitic disease endemic to the Nile Delta. At the time, intravenous injection of tartar emetic was the standard treatment. More than two million injections were given to approxi-

mately 250,000 persons annually.<sup>28</sup> Glass syringes were used—and reused—during this campaign, and sterilization was inadequate to inactivate the hepatitis C virus (HCV), which was not known to medical science at the time. Epidemiologic evidence suggests that this resulted in large-scale iatrogenic transmission of HCV, although other sources of transmission likely occurred as well.<sup>29</sup> The prevalence of HCV infection in Egypt is now among the highest in the world.<sup>30</sup>

These four examples illustrate specific types of unintended harm that can occur in global health practice. In the first scenario, harm may have resulted from a physician not providing medical care that was unrelated to the specific health project on which he was working. That the health outcome remains unknown is indicative of the extent to which the physician, for a variety of reasons, turned away from a direct, personal appeal for help. This is an example of potential harm by omission during the course of fieldwork. It also illustrates the problem of dual loyalties, which arises frequently in global health practice.<sup>31</sup> In this case, the moral claim on the physician to attend to the “patient” in front of him was in conflict with his responsibilities as a public health worker on a specific project.

In the second scenario, although the relationship between mass treatment for lymphatic filariasis and the miscarriage was uncertain, the team discussed—at length—what to do. They decided to return to the village where the woman lived and to apologize. Dr. King explained, “We sat down with the family. We explained why we were doing this research, that it was a mistake on our part if we gave her the drug without asking about her last period. We asked if they would accept our apology. Sitting down with them provided an opportunity for us to accept some responsibility for the mistake and to let them know that we would do our best to ensure that we wouldn’t give the drug to pregnant women in the future.”<sup>32</sup> The apology was accepted, the relationship between researchers and the community was restored, and the project continued.

In the third scenario, a surveillance system for serious adverse events during mass drug administration identified an unusual cluster of cases that

was unexpected. An international investigation was launched to identify the etiology, further define risk, understand pathogenesis, and develop alternate treatment strategies.<sup>33</sup> Several measures were taken to prevent and reduce the severity of further cases, including enhanced adverse event surveillance and reporting, improved clinical care for persons with neurological complications, and halting the onchocerciasis control program in areas known to be endemic for *Loa loa* until safeguards could be put in place.

In the fourth scenario, the first publications linking HCV with the schistosomiasis campaign did not appear until 1994, more than 10 years after parenteral antischistosomal therapy was replaced by an effective oral medicine.<sup>34</sup> The initial response to the HCV epidemic was slow, compounded by the lack of effective treatment for HCV infection. In the past few years, the Egyptian government has prioritized HCV treatment and, with the development of new drugs that can effectively cure infection, has expanded its program and launched a large-scale treatment and prevention plan that would set Egypt on a path toward eliminating HCV as a public health problem.<sup>35</sup> Although government officials have not provided a formal apology to persons infected through the schistosomiasis campaign, the plan to offer HCV treatment free of charge could be seen, in part, as a form of collective responsibility to redress harm.

## Discussion

These four scenarios represent a range of unintended harm—and response. We now discuss, in the context of global health programs: (1) barriers to acknowledging and disclosing unintended harm when it occurs; (2) challenges to offering apology and reparation; and (3) legal perspectives and human rights approaches to acknowledging and addressing unintended harm.

### *Barriers to acknowledging unintended harm in global health*

Several features of global health practice contribute to the difficulty of acknowledging and adequately

addressing unintended harm, including inadequate surveillance for unanticipated harm; fears of liability or perceived threats to programs; imbalances of power; and the self-image of practitioners and their organizations.

#### **Inadequate surveillance for unanticipated harm.**

Before public health interventions such as vaccines and medicines are implemented at scale, they typically undergo rigorous clinical testing for safety and efficacy. However, the sample size of clinical trials and pilot projects are usually too small to detect rare adverse events or to ensure safety in areas where the intervention has not been tested, as was the case with ivermectin and *Loa loa*. With health promotion efforts that may result in stigma or other social disruption, differences in culture and legal environments can lead to dramatically different results depending on the setting or population. Robust surveillance for unanticipated harm can be quite difficult in remote areas with limited public health infrastructure. Further, for rare events or complex social phenomena, data are often inadequate to reliably infer a causal link between an intervention and a harm. With interventions that are believed to be safe and effective, public health programs typically allocate their limited resources to delivering the benefits of those interventions to the populations who need them, rather than investing in surveillance systems to detect harm.

#### **Liability and perceived threats to programs.**

When unintended harm occurs in the context of large-scale interventions intended to protect the health of populations, there may be concern that disclosing it could threaten the program in question, result in unwanted negative publicity, and jeopardize the substantial public health benefits that the program delivers. These effects, although initially limited to a single program, can quickly undermine trust in public health institutions more broadly. Apologizing where causality is uncertain (as in scenario 2) could imply acceptance of responsibility and increase liability, especially for international donors and corporate partners, which are vulnerable to lawsuits.

**Power imbalances.** Solidarity with those from whom we are separated by geography, income, culture, or power is a core value of global health.<sup>36</sup> Even so, it may be difficult for persons who occupy positions of power and wealth to recognize the impact of unintended harm when it occurs in someone who is already marginalized, geographically distant, and with limited resources and means to demand attention or compensation. In global health practice, therefore, imbalances in power can predispose program implementers to the same blind spots that contribute to ethical lapses in clinical trials, which arise from a lack of awareness, understanding, or concern for the impact of one's decisions on the lives of human beings.

**Self-image.** To truly apologize requires vulnerability, as the apology may not be accepted. When one's identity is wrapped up with doing good or rescuing others, acknowledging harm represents a threat to self-image. Physicians take an oath to "do no harm." When their best efforts result not in healing, but in injury or harm, their personal identity and professional reputation may be threatened. This also holds true for global health organizations, which align themselves with altruistic values and principles. Over-identification with self-narratives of "helping" or "doing good" creates powerful internal incentives for discounting evidence that one's actions have had unintended adverse consequences. Such over-identification also makes it difficult to effectively recognize and navigate dual loyalties.

#### *Challenges to offering apology and reparation*

Several features of global health practice contribute to the difficulty of offering apology and reparation, including the global scale of the enterprise; lack of clarity regarding blame or responsibility; discordant values; and inadequate attention to relationships of trust.

**Scale.** Global health operates simultaneously at multiple levels and across huge geographic, cultural, and economic distances. Interventions may be designed in the boardrooms of international organizations,

but they are ultimately implemented in local communities.<sup>37</sup> On the one hand, the global nature of the field requires that interventions, to some degree, be standardized and delivered in collaboration with international programs to achieve global goals. On the other hand, global programs are enacted at the local level, requiring the engagement of affected persons and communities. Inevitable tensions arise between unified “cookbook” approaches to achieve global targets and a multitude of divergent realities on the ground. Despite lip service to “stakeholder engagement,” we still don’t practice it consistently or particularly well.<sup>38</sup>

At the community level, where personal relationships are at stake, it is likely that apology *is* offered when health interventions are associated with actual or perceived harm. In our second scenario, the investigators realized that a breach in trust with the community could signal the end of their project. The causal relationship between the drug and the miscarriage was uncertain. The investigators believed that they had asked the woman about the date of her last menstrual period, which is the recommended approach for excluding pregnant women from receiving mass treatment for lymphatic filariasis. But this had not been documented.

The apology in this case was relatively private—similar to what might happen in medical settings. The project team acknowledged the uncertainty surrounding causality, as well as the possibility that they had committed error in not asking the woman about her last menstrual period. They were not official representatives of the global program to eliminate lymphatic filariasis but rather a team of researchers and local collaborators—persons who would likely function as community drug distributors when mass drug administration was implemented. They resided in the local communities and could readily understand and “see the faces” of their study subjects. The apology was apparently accepted and allowed the investigators to proceed, even in the absence of reparation.

The researchers’ motives likely included a sincere desire to restore human relationships, but they also needed the cooperation of the community to continue their work. In addition to being the “right”

thing to do at a human level, the apology had practical implications for the project. We lack information from the perspective of the woman and her family, but the project team reports that the woman found some comfort in knowing that the miscarriage may have had an external or medical cause.

As scale increases, so do social distance, ambiguity with regard to responsibility, and the personal and organizational stakes in assuming “blame” for unintended harm. Indeed, it may not always be clear exactly what a given individual in global health should apologize for, on whose behalf, or whether an apology is “authorized.” Consequentially, apology and restoration of relationships are often more difficult than in scenario 2. The latter two scenarios describe unintended harm that occurred over a period of years in the context of major public health programs involving national governments and external partners. While personal apology at the individual level may be offered more often than we think in such situations, formal apology that addresses all affected persons is uncommon. The political, legal, and organizational complexity of global health partnerships makes it difficult. More often, when unintended harm or error *is* acknowledged in global health practice, the response focuses on the future—in other words, preventing repeated harm rather than addressing the rift in relationships or rebuilding trust.

At the local level, community health workers straddle this global-local divide. They function as cultural translators and intermediaries between a global program and its local implementation; they are agents of a global enterprise, while also members of the local community. Recent evidence indicates that attending to these different roles can involve considerable stress, particularly in addressing unintended harm.<sup>39</sup>

**Lack of clarity for responsibility.** As already noted, responsibility for harm in global health programs is often multifactorial and diffuse, dispersed among a host of local, national, and international actors. The responsibility for offering apology does not necessarily coincide with responsibility for reparation.

An example of the difficulty of assigning re-



sponsibility for unintended harm in global health comes from mass drug treatment programs for soil-transmitted helminths, or intestinal worms. More than 150 million preschool-age children receive deworming medicine every year through mass treatment.<sup>40</sup> A small (but unacceptable) number have fatally choked on the tablets.<sup>41</sup> The limited evidence available suggests that this occurs primarily when children are frightened or fussy and resist taking the tablets. In such cases, who is responsible? Is it the health care worker or parent who administered the medicine to the child with the intention of improving the child's health, the nongovernmental organization (NGO) that sponsored the deworming, the national and provincial ministries of health that authorized it, the World Health Organization and global health experts who encouraged high drug coverage to achieve important public health goals, the pharmaceutical company that manufactured the medicine—or no one?

In addition, while individual physicians are licensed (and subject to sanction) by the state, and the actions of public health officials are authorized by the government (and can include police powers of detention and quarantine), global health as a field lacks a corresponding authorizing agency. Each global health organization is charged by its governing board with advancing a certain agenda or serving specific functions. For example, the World Health Organization acts on behalf of its member states, and the US Agency for International Development is authorized and funded by US Congress. Global health governance remains fragmented and chaotic: an amalgam of diverse interests, sectors, and influences ranging from faith-based organizations to the military.<sup>42</sup> Consequently, authority for program implementation and for addressing unintended harm is often shared and is sometimes ambiguous. Individuals working in global health rarely question their “authority” to act, relying on personal values and motivations or their institution's operational guidelines. This “devolution to individual moral latitudes,” as described by Petryna, provides global health practitioners with little clear guidance and can lead to ethical variability.<sup>43</sup>

**Lack of consensus on core values.** While Solomon Benatar and others have written on the core values of global health, in practice these values are assumed and implicit.<sup>44</sup> The degree to which core values are actually shared and understood across all partners is uncertain. Further, the priorities of organizations engaged in global health can diverge significantly, especially during times of social unrest or fear, or in relation to interventions addressing criminalized populations or stigmatized behaviors. For some interventions—for example, those targeting open defecation or tobacco control—stigma may be both the strategy and the intended result. The lack of an explicit collective understanding of, and commitment to, core values complicates both the recognition of unintended harm and the response to it. Particularly in cases where political determinants of health (such as repressive laws and policies) lead to harm, health interventions may counter these harms or unintentionally be complicit with them.<sup>45</sup>

**Trust.** At all levels, the success of global health programs depends on a high degree of trust and social capital among individuals. When these are present, stakeholders and representatives of specific institutions can transcend partisan interests and work together toward a shared vision of health for *all* peoples.<sup>46</sup> It is easier to maintain (or assume) this trust when things are working well. In times of stress or crisis, however, or when unintended harm occurs, it is natural for individuals and organizations to want to avoid blame and protect their own interests and strategic objectives. The resulting retrenchment undermines trust—and hurts programs.

#### *Legal issues, human rights, and apology for unintended harm in global health*

At first glance, apology seems disconnected from the notion of human rights. While there is not a *right* to apology per se, public apologies, particularly on behalf of states, are increasingly common in an effort to heal social rifts resulting from systemic human rights abuses. However, they are often criticized as insincere, half-hearted, and lacking adequate reparation.<sup>47</sup> To be effective, public apologies must be carefully planned, sincerely offered,

and accompanied by reparation.<sup>48</sup>

Because global health operates at local, national, and global levels, unintended harm, when it occurs, must be acknowledged and addressed at all of these levels. Global health actors—whether funded by states and acting in quasi-state roles or privately funded—work within legal frameworks at the local and national levels, even if they are ignorant of this fact and see themselves as separate from them. They also operate within a global legal framework, which is conceptualized and enacted through the language and principles of human rights, specifically the right to health. These principles are enshrined in the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, and other relevant conventions, such as the Convention on the Rights of the Child.<sup>49</sup>

How might a human rights approach inform acknowledgement of harm, apology, and reparation in global health practice? First, it is important to recognize that global health programs and human rights frameworks share key norms and standards of practice, as well as legal duties, including informed consent, community engagement, monitoring, and reporting. Since the state is obligated to respect, protect, and fulfill the right to health, the state—and, by extension, non-state actors working under the authority of the state—have obligations to ensure the protection and promotion of key rights, including participation and non-discrimination in all health interventions.<sup>50</sup> When this link between global health goals and human rights obligations is openly acknowledged, it is easier to imagine global health practitioners looking to human rights standards and authorities to address harm when it occurs, either as breach of duty (whether intentional or unintentional) or as a result of unforeseen circumstances, despite meeting standards of care.

The United Nations Committee on Economic, Social and Cultural Rights, in its General Comment 14, provides an authoritative interpretation of states' obligations with respect to the right to health.<sup>51</sup> There is no mention of apology in this general comment. The document does, however,

discuss “remedies and accountability” (paras. 59–62), emphasizing “access to effective judicial or other appropriate remedies at both national and international levels” and “adequate reparation, which may take the form of restitution, compensation, satisfaction or guarantees of non-repetition” (para. 59). Specific mention is made of “national ombudsmen, human rights commissions, consumer forums, patients' rights associations or similar institutions” to address violations of the right to health. The general comment also describes the equivalent obligations of non-state actors (paras. 63–65).

Meanwhile, the United Nations Human Rights Committee, which provides authoritative interpretation of the International Covenant on Civil and Political Rights, has noted that, “where appropriate, reparation can involve restitution, rehabilitation and measures of satisfaction, such as *public apologies*, public memorials, guarantees of non-repetition and changes in relevant laws and practices, as well as bringing to justice the perpetrators of human rights violations” (emphasis added).<sup>52</sup>

The United Nations Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law provides another resource for examining the basis for remedies in the case of unintended harm in global health interventions. These principles were the result of a 15-year process of study, negotiations, and drafting on the part of the United Nations Sub-Commission on the Promotion and Protection of Human Rights and the United Nations Commission on Human Rights. They represent the first comprehensive codification of the rights to reparation by victims of mass human rights violations. The Basic Principles acknowledge that appropriate reparations depend on the gravity of the violation and the harm suffered, as well as the circumstances of each case, but they also state that forms of reparation that must be considered include restitution, compensation, rehabilitation, satisfaction, and guarantees of non-repetition.<sup>53</sup>

Notwithstanding these human rights obli-

gations, within the United States, international organizations such as the United Nations and its programs and specialized agencies such as the United Nations Children's Fund and the International Finance Corporation (IFC), enjoy immunity from lawsuits. The extent of that immunity was recently challenged in a case before the Supreme Court involving environmental harm that affected a community of farmers and fishermen whose lives and livelihoods were negatively affected by the construction of a coal-fired power plant partially funded by the IFC in Gujarat, India.<sup>54</sup> The Supreme Court rejected the IFC's claims of absolute immunity and, without judging on the merits of the case, pointed to the IFC's failure to respond to its own internal audit, which found that the institution had not adequately monitored or responded to the project's environmental and social impacts.<sup>55</sup>

Notwithstanding the recent IFC case, the difficulty of realizing rights protections and the limits of courts to redress claims suggests the need for other means of accountability, such as quasi-judicial mechanisms. For example, in 19 countries, review boards can offer financial compensation to persons who suffer serious adverse reactions following vaccination.<sup>56</sup> In doing so, vaccine injury compensation programs recognize the low—but present—level of risk that individuals inherently accept on behalf of the public good. These programs also acknowledge a societal obligation to recognize and address unintentional harm when it occurs.

## Challenges and implications

Worldwide, more than US\$150 billion is invested annually in international health and development assistance.<sup>57</sup> Given the sheer volume and complexity of this effort, mistakes sometimes happen and unintended harm occurs. We presented four scenarios from neglected tropical disease control programs, but examples can be found throughout the field of global health. The challenge remains: How do these accounts get acknowledged, reported, addressed, and incorporated into a global health system that ensures accountability and redress? How can we learn from our mistakes, even if unintended, and

prevent them in the future? Our goal in this paper has been to consider how examples of unintended harm can help global health practitioners learn and grow, rather than seek to forget and move on.

We have explored several challenges and barriers to acknowledging harm and to offering apology and reparation in global health, which include structural, psychological, economic, legal, and cultural factors. Given the enormous complexity of global health, it is not surprising that apology is so difficult. At the heart of apology lies human relationships, whether among individuals linked together by shared interests or friendship, organizations with contractual agreements, or governments bound by international obligations. Too often, our relational assumptions and agreements in global health are implicit and assumed rather than explicit. Further, power dynamics complicate decisions about apology and compensation for harm. Within these networks of relationships, who determines what is “fair” and when compensation is warranted? Apology—and even compensation—can be misused, offered prematurely to avoid a much-needed conversation, or used as a risk-management strategy. In such cases, the person harmed or whose rights have been violated may desire neither apology nor restoration of the relationship.

The great challenge and paradox of global health is that it is simultaneously global in scope and, of necessity, undertaken at the community level. What is appropriate at the global level may be inappropriate or ineffective at the local level, and vice versa. In writing about the complex process of peacebuilding, John Paul Lederach notes that true reconciliation takes place in communities.<sup>58</sup> Peace treaties mean little if neighbors remain estranged and in fear. While public ceremonies of remorse, apology, and even reparation have an important—albeit underutilized—role in global health, they do not replace the need for private apology at the individual or community level.

This leads us back to the necessity of community engagement in global health programs. When programs are designed and implemented with full community engagement, deciding whether and how to apologize can be considered in partnership



with community leaders. We suspect that in such cases, apology may be more natural, easier, and less frequently needed. Top-down approaches tend to increase the likelihood of breaches in trust and the subsequent need for apology. They also make it more difficult for apology to be effective because, in the words of Bill Foege, “the faces” of affected individuals have not been fully seen.<sup>59</sup>

## Recommendations

We close by offering a few reflections and suggestions on how we in global health might better address unintentional harm at three levels: individual, organizational, and global.

At the individual level, developing relationships of trust, grounded in respect for human rights, is critical. Global health practitioners should develop the capacity to recognize when trust has been breached and actively monitor for unintended harm. Skillfully applying the art of apology requires a high degree of self-awareness, the ability to connect with others, a commitment to solidarity and other core values, a willingness to question our assumptions, and humility. It also requires awareness of, and respect for, the personally corrosive effects of unacknowledged harm—including moral distress and moral residue.<sup>60</sup> Knowing when and how to disclose error and offer apology is much easier when one’s actions are not clouded by compulsion, one is not over-identified with specific outcomes, and one is open to learning of one’s ethical blind spots.

At the organizational level, a commitment to acknowledging and addressing inadvertent harm is essential for sustained programmatic excellence. Organizations implementing global health programs should become more aware of human rights frameworks and their ethical and legal obligations as non-state actors.<sup>61</sup> Practitioners and students would benefit from training in apology, as is increasingly provided for medical students and residents.

Ethics in global health is rarely about “getting it right” once and for all. Rather, human rights and ethical principles demand that we continuously monitor our programs to maximize their benefits and minimize any harm that they might cause. Or-

ganizations engaged in global health practice would benefit from the type of self-evaluation processes that the Research Fairness Initiative recommends for research institutions.<sup>62</sup> Additional approaches could include specific consideration of apology and reparation within memoranda of understanding and accountability frameworks between governments and NGO partners. Program plans, research protocols, and institutional review boards could more specifically address the responsibilities of individuals, as well as institutions, for responding to unintended harm.

At the global level, acknowledging and satisfactorily addressing unintended harm remain difficult. As we have noted, global health programs are more likely to respond with efforts to prevent future harm than they are to look backward to make reparation. National vaccine injury compensation schemes offer an interesting exception to this rule and provide a model that could be adopted by other countries, as well as expanded to the global level, as proposed by Sam Halabi and Saad Omer.<sup>63</sup>

Further work is needed to develop a framework for addressing unintended harm in global health. This framework should draw on and link to the United Nations declarations, covenants and other legal documents mentioned above. It should also be informed by a wide range of examples of unintended harm and developed through a participative process that includes government agencies, donors, NGOs, and communities. The role of apology and reparation in specific global health situations will likely vary depending on several factors, including the severity of harm; whether harm is caused by an individual, an organization, or a diffuse network of organizations; and whether it results from error, either technical or in judgment, moral wrongdoing, incompetence, negligence, failure to act, or some unforeseeable event.

The year 2020 represents a milestone for many global health programs. The global health community will rightly celebrate the impressive progress and health benefits that have been realized. Yet, along the way, some individuals have suffered harm. While celebrating success, might we also remember those who have been inadvertently harmed despite

our good intentions? Even if personal apology and reparation for affected individuals are not possible, acknowledging unintended harm could provide opportunities to attend to the relational dimensions of global health, promote human rights, foster human dignity, and minimize harm while pursuing the highest attainable level of health for all peoples.<sup>64</sup>

## References

1. A. Glassman and M. Temin, *Millions saved: New cases of proven success in global health* (Washington DC: Center for Global Development, 2016).
2. N. A. Y. Twum-Danso, "Loa loa encephalopathy temporally related to ivermectin administration reported from onchocerciasis mass treatment programs from 1989 to 2001: Implications for the future," *Filaria Journal* 2/Suppl 1 (2003), p. s7; K. Andrinopoulos, J. P. Figueroa, D. Kerrigan, and J. M. Ellen, "Homophobia, stigma and HIV in Jamaican prisons," *Culture, Health and Sexuality* 13/2 (2011), pp. 187–200.
3. L. K. Allen-Scott, J. M. Hatfield, and L. McIntyre, "A scoping review of unintended harm associated with public health interventions: Towards a typology and an understanding of underlying factors," *International Journal of Public Health* 59 (2014), pp. 3–14; P. J. Fleming, J. G. Lee, and S. L. Dworkin, "Real men don't: Constructions of masculinity and inadvertent harm in public health interventions," *American Journal of Public Health* 104/6 (2014), pp. 1029–1035; F. Fürst and K. Birdsall, "Reducing the environmental cost of saving lives," *Healthy Development* (March 2019). Available at [http://health.bmz.de/events/In\\_focus/reducing\\_environmental\\_cost\\_saving\\_lives/index.html](http://health.bmz.de/events/In_focus/reducing_environmental_cost_saving_lives/index.html).
4. D. S. Silva, M. J. Smith, and R. E. G. Upshur, "Disadvantaging the disadvantaged: When public health policies and practices negatively affect marginalized populations," *Canadian Journal of Public Health* 104/5 (2013), pp. e410–e412.
5. L. T. Kohn, J. M. Corrigan, and M. S. Donaldson (eds), *To err is human: Building a safer health system* (Washington, DC: Committee on Quality of Health Care in America, Institute of Medicine, 2000).
6. N. Berlinger, *After harm: Medical error and the ethics of forgiveness* (Baltimore: Johns Hopkins University Press, 2005), p. 61.
7. *Ibid.*, p. 66.
8. A. W. Wu, D. J. Boyle, G. Wallace, and K. M. Mazor, "Disclosure of adverse events in the United States and Canada: An update, and a proposed framework for improvement," *Journal of Public Health Research* 2 (2013), p. e32.
9. J. K. Robbennolt, "Apologies and medical error," *Clinical Orthopaedics and Related Research* 467 (2009), pp. 376–382.
10. Berlinger (see note 6).
11. A. Petryna, "Ethical variability: Drug development and globalizing clinical trials," *American Ethnologist* 32/2 (2005) pp. 183–197.
12. J. H. Jones, *Bad blood: The Tuskegee syphilis experiment* (New York: Free Press, 1981).
13. Presidential Commission for the Study of Bioethical Issues, "Ethically impossible" *STD research in Guatemala from 1946 to 1948* (September 2011). Available at [https://bioethicsarchive.georgetown.edu/pcsbi/sites/default/files/Ethically%20Impossible%20\(with%20linked%20historical%20documents\)%202.7.13.pdf](https://bioethicsarchive.georgetown.edu/pcsbi/sites/default/files/Ethically%20Impossible%20(with%20linked%20historical%20documents)%202.7.13.pdf).
14. V. M. Mays, "The legacy of the U. S. Public Health Services study of untreated syphilis in African American men at Tuskegee on the Affordable Care Act and health care reform fifteen years after President Clinton's apology," *Ethics and Behavior* 22/6 (2012), pp. 411–418.
15. H. J. Carmack, B. R. Bates, and L. M. Harter, "Narrative constructions of health care issues and policies: The case of president Clinton's apology-by-proxy for the Tuskegee syphilis experiment," *Journal of Medical Humanities* 29 (2008), pp. 89–109.
16. Office of the Spokesman, US Department of State, *Joint statement by secretaries Clinton and Sebelius on a 1946-1948 study* (October 1, 2010). Available at <https://2009-2017.state.gov/secretary/20092013clinton/rm/2010/10/148464.htm>.
17. *Estate of Alvarez v. Johns Hopkins University*. (United States District Court, D. Maryland, Civil Action No. MJG-15-950, Aug 30, 2017).
18. B. Spielman, "Effective reparation for the Guatemala S.T.D. experiments: A victim-centered approach," *Kennedy Institute of Ethics Journal* 28/2 (2018), pp. 145–170.
19. COHRED, *Research Fairness Initiative*. Available at <http://rfi.cohred.org>.
20. J. J. Amon, S. D. Baral, C. Beyrer, and N. Kass, "Human rights research and ethics review: Protecting individuals or protecting the state?," *PLoS Medicine* 9/10 (2012), p. e1001325.
21. Allen-Scott et al. (see note 3).
22. T. Lorenc and K. Oliver, "Adverse effects of public health interventions: A conceptual framework," *Journal of Epidemiology and Community Health* 68/3 (2014), pp. 288–290.
23. J. Watts, "Japanese leprosy patients receive official apology," *Lancet* 357/9270 (2001), p. 1774; "Liberian president apologizes to health care workers for Ebola deaths," *NBC News* (August 9, 2014). Available at <https://www.nbcnews.com/storyline/ebola-virus-outbreak/liberian-president-apologizes-health-care-workers-ebola-deaths-n177056>.
24. M. Boussinesq, "Ivermectine," *Medicine Tropicale* 65/1 (2005), pp. 69–79.
25. T. C. Bailey, M. W. Merritt, and F. Tediosi, "Investing in justice: Ethics, evidence, and the eradication investment cases for lymphatic filariasis and onchocerciasis," *American*

*Journal of Public Health* 105 (2015), pp. 629–636.

26. M. Homeida, E. Braide, E. El Hassan, et al., “APOC’s strategy of community-directed treatment with ivermectin (CDTI) and its potential for providing additional health services to the poorest populations,” *Annals of Tropical Medicine and Parasitology* 96/Suppl 1 (2002), pp. S93–S104.

27. M. Boussinesq, M. Gardon, J. Kamgno, et al., “Relationships between the prevalence and intensity of Loa loa infection in the Central province of Cameroon,” *Annals of Tropical Medicine and Parasitology* 95 (2001), pp. 495–507.

28. C. Frank, M. K. Mohamed, G. T. Strickland, et al., “The role of parenteral antischistosomal therapy in the spread of hepatitis C virus in Egypt,” *Lancet* 355/9207 (2000), pp. 887–891.

29. M. A. Darwish, R. Faris, N. Darwish, et al., “Hepatitis C and cirrhotic liver disease in the Nile delta of Egypt: A community-based study,” *American Journal of Tropical Medicine and Hygiene* 64/3–4 (2001), pp. 147–153.

30. World Bank, *Egypt’s viral hepatitis program – Burden and response: An economic analysis* (Washington, DC: World Bank, 2017).

31. L. Briskman and D. Zion, “Dual loyalties and impossible dilemmas: Health care in immigration detention,” *Public Health Ethics* 7 (2014), pp. 277–286.

32. Center for Compassion and Global Health, *The value of apology: Communication, restitution, and relationship; A conversation with Chris King*. Available at <http://ccagh.org/conversations/personal-stories/chris-king/>.

33. J. Kamgno, S. D. Pion, C. B. Chesnais, et al., “A test-and-not-treat strategy for onchocerciasis in Loa loa-endemic areas,” *New England Journal of Medicine* 377/21 (2017), pp. 2044–2052.

34. M. F. Abdel-Wahab, S. Zakaria, M. Kamel, et al., “High seroprevalence of hepatitis C infection among risk groups in Egypt,” *American Journal of Tropical Medicine and Hygiene* 51/5 (1994), pp. 563–567.

35. A. Elgharably, A. I. Gomaa, M. M. E. Crosse, et al., “Hepatitis C in Egypt: Past, present, and future,” *International Journal of General Medicine* 10 (2017), pp. 1–6.

36. S. R. Benatar, A. Daar, and P. A. Singer, “Global health ethics: The rationale for mutual caring,” *International Affairs* 79/1 (2003), pp. 107–138.

37. K. L. Bardosh, “Towards a science of global health delivery: A socio-anthropological framework to improve the effectiveness of neglected tropical disease interventions,” *PLoS Neglected Tropical Diseases* 12/7 (2018), p. e0006537.

38. J. V. Lavery, “Building an evidence base for stakeholder engagement,” *Science* 361/6402 (2018), pp. 554–556.

39. A. Krentel, M. Gyapong, S. Mallya, et al., “Review of the factors influencing the motivation of community drug distributors towards the control and elimination of neglected tropical diseases (NTDs),” *PLoS Neglected Tropical Diseases* 11/12 (2017), p. e0006065.

40. World Health Organization, “Schistosomiasis and

soil-transmitted helminthiasis: Number of people treated in 2016,” *Weekly Epidemiological Record* 92 (2017), pp. 749–760.

41. J.W. Kernell, R. V. DePaola, A. M. Maglione, et al., “Risk of adverse swallowing events and choking during deworming for preschool-aged children,” *PLoS Neglected Tropical Diseases* 12/6 (2018), p. e0006578.

42. J. Frenk and S. Moon, “Governance challenges in global health,” *New England Journal of Medicine* 368 (2013), pp. 936–942.

43. A. Petryna, *When experiments travel: Clinical trials and the global search for human subjects* (Princeton, NJ: Princeton University Press, 2009).

44. Benatar et al. (see note 36).

45. J. J. Amon, “The political epidemiology of HIV,” *Journal of the International AIDS Society*, 17/1 (2014), p. 19327; I. W. Todrys, E. Howe, and J. J. Amon, “Failing Siracusa: Governments’ obligations to find the least restrictive options for tuberculosis control,” *Public Health Action* 3/1 (2013), pp. 7–10; J. J. Amon, R. Pearshouse, J. E. Cohen, and R. Schleifer, “Compulsory drug detention in East and Southeast Asia: Evolving government, UN and donor responses,” *International Journal of Drug Policy* 25/1 (2014), pp. 13–20.

46. World Health Organization, *WHO Constitution* (Geneva: World Health Organization, 1946).

47. P. Alston, *Extracting accountability: Special rapporteurs and the United Nations’ responsibility for cholera in Haiti*, NYU School of Law, Public Law Research Paper No. 18-10 (February 2018). Available at <https://ssrn.com/abstract=3125084>.

48. R. Carranza, C. Correa, and E. Naughton, *More than words: Apologies as a form of reparation* (New York: International Center for Transitional Justice, 2015).

49. Universal Declaration of Human Rights, G.A. Res. 217A (III) (1948); International Covenant on Civil and Political Rights, G.A. Res. 2200A (XXI) (1966); International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI) (1966); Convention on the Rights of the Child, G.A. Res. 44/25 (1989).

50. D. Barr, J. Amon, and M. Clayton, “Articulating a rights-based approach to HIV treatment and prevention interventions,” *Current HIV research* 9/6 (2011), pp. 396–404.

51. Committee on Economic, Social and Cultural Rights, General Comment No. 14, The Right to the Highest Attainable Standard of Health, UN Doc. E/C.12/2000/4 (2000).

52. Human Rights Committee, General Comment No. 31, Nature of the General Legal Obligation on States Parties to the Covenant, UN Doc. CCPR/C/21/Rev.1/Add.13 (2004), para. 16.

53. UN General Assembly, Res. 60/147, UN Doc. A/RES/60/147 (2006).

54. K. Daugirdas, “Can you sue international organizations? The Supreme Court decides to weigh in,” *Just Security* (June 1, 2018). Available at <https://www.justsecurity.org/57265/sue-international-organizations-su->

preme-court-decides-weigh.

55. D. Desierto, "SCOTUS Decision in *Jam et al v. International Finance Corporation (IFC) Denies Absolute Immunity to IFC ...With Caveats*," *EJIL: Talk! Blog of the European Journal of International Law* (February 28, 2019). Available at <https://www.ejiltalk.org/scotus-decision-in-jam-et-al-v-international-finance-corporation-ifc-denies-absolute-immunity-to-ifc-with-caveats>.

56. C. Looker and H. Kelly, "No-fault compensation following adverse events attributed to vaccination: A review of international programmes," *Bulletin of the World Health Organization* 89 (2011), pp. 371-378.

57. World Bank, *Net official development assistance and official aid received (current US\$)*, (2019). Available at <https://data.worldbank.org/indicator/dt.oda.alld.cd>.

58. J. P. Lederach and A. J. Lederach, *When blood and bones cry out: Journeys through the soundscape of healing and reconciliation* (New York: Oxford University Press, 2010).

59. W. H. Foegen, *Smallpox, Gandhi and CDC: Fifth annual Joseph Mountin lecture* (Atlanta: Centers for Disease Control, 1984).

60. E. G. Epstein and S. Delgado, "Understanding and addressing moral distress," *Online Journal of Issues in Nursing* 15/3 (2010).

61. N. Sun and J. J. Amon, "Addressing inequity: Neglected tropical diseases and human rights," *Health and Human Rights Journal* 20/1 (2018), p. 11.

62. COHRED (see note 19).

63. S. F. Halabi and S. B. Omer, "A global vaccine injury compensation system," *Journal of the American Medical Association* 317/5 (2017), pp. 471-472.

64. World Health Organization (see note 46).

# An Assessment of Human Rights-Based Approaches to Health Knowledge, Attitudes, and Practices Among Centers for Disease Control and Prevention Locally Employed Staff

IZRAELLE MCKINNON, AUN LOR, AND DABNEY P. EVANS

## Abstract

Despite the increasing use of human rights-based approaches to health, the Centers for Disease Control and Prevention (CDC) does not routinely train its staff in the use of such approaches as a part of public health practice. We conducted a training needs assessment among CDC locally employed staff working outside of the United States through eight key informant interviews and an online survey from June to December 2015. Key informants revealed an awareness that rights violations negatively affect access to health services and supported implementation of formal training among CDC staff. Most (82%) survey respondents felt that the CDC should do more to address health and human rights issues in its programs, policies and research. However, 72% of respondents did not feel they had adequate knowledge to address human rights in their work. In particular, 86% of participants had no knowledge of the Siracusa Principles (criteria for human rights restrictions) and only 2% of participants had received any training on international human rights treaties related to the duties of public health professionals. Our findings inform and support the need to design a training on human rights-based approaches to health, focused on the knowledge and skill needs of CDC locally employed staff.

---

IZRAELLE MCKINNON, MPH, is a PhD student in epidemiology at Emory University, Atlanta, GA, USA.

AUN LOR, MPH, MA, PhD, is Deputy Associate Director for Science in the Center for Global Health at the US Centers for Disease Control and Prevention, Atlanta, GA, USA.

DABNEY P. EVANS, PhD, MPH, is an associate professor in the Hubert Department of Global Health and Executive Director of the Institute of Human Rights at Emory University, Atlanta, GA, USA.

Please address correspondence to Dabney P. Evans. Email: [devan01@emory.edu](mailto:devan01@emory.edu).

Competing interests: None declared.

Copyright © 2019 McKinnon, Lor, and Evans. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted noncommercial use, distribution, and reproduction in any medium, provided the original author and source are credited. AL was an employee of the US Federal Government when this work was conducted and prepared for publication; therefore, it is not protected by the Copyright Act.

Disclaimer: The findings and conclusions in this report are those of the author(s) and do not necessarily represent the official position of the Centers for Disease Control and Prevention.



## Introduction

The use of international human rights standards, bodies, and mechanisms to further the realization of human rights, known as human rights-based approaches (HRBAs), is one strategy for achieving the highest attainable standard of health for all.<sup>1</sup> The civil, cultural, economic, political, and social rights described within human rights documents define the basic societal conditions necessary to achieve health, providing a framework for health policy and programming.<sup>2</sup> Human rights documents, therefore, either explicitly or implicitly inform the duties of health professionals.<sup>3</sup> For example, the Siracusa Principles are a set of legally agreed-upon guidelines to be followed in situations in which actors, such as health professionals acting on behalf of the state, must restrict human rights and civil liberties to protect the health of the community.<sup>4</sup> At times, public health professionals have the authority to use rights-restricting measures to protect population health, particularly in disease control and prevention, and during health emergencies.<sup>5</sup>

Moreover, HRBAs identify the importance of not just the outcomes of public health practice, but necessary processes for public health practice.<sup>6</sup> The World Health Organization (WHO) posits that human rights standards and principles—such as participation, accountability, equality and non-discrimination—can be integrated into all aspects of public health practice, including assessment and analysis, priority setting, program planning and design, implementation, and monitoring and evaluation.<sup>7</sup> As a result, HRBAs develop individual and health systems by providing skills and resources to support ethical, sustainable, and improved outcomes. State actors, or duty bearers, in particular are better equipped to meet their obligations to respect, protect, and fulfill the right to health through understanding and utilizing HRBAs.<sup>8</sup> Furthermore, human rights instruments, bodies, and mechanisms provide the political power and legal obligations to effect societal conditions by holding duty bearers accountable to their practices and outcomes.<sup>9</sup>

The need to address inequalities, discriminatory practices, and injustices that obstruct the

fulfillment of human rights—including the right to health—provides the foundation for use of HRBAs. General Comment 14 provides an extensive interpretation of the right to health and the manner in which states must engage with that right; it discusses explicitly the nature of human rights as interdependent and interrelated—the violation or fulfillment of one right affecting the ability of individuals to achieve other rights.<sup>10</sup> The potential to realize the right to health for all is dependent upon the realization of other social factors which are the underlying determinants of health, including food, housing, safe water and working conditions, and a healthy environment.<sup>11</sup> Importantly, public health professionals—because of their role in the investigation of health needs, development of programs, and implementation of policy—play a unique role in impacting health-related human rights.<sup>12</sup> An understanding of the relationship between health and human rights and the use of HRBAs among health professionals prevents discriminatory, coercive, or otherwise harmful practices in public health.<sup>13</sup>

HRBAs training for health professionals has been shown to improve identification of vulnerable groups, their health needs, and underlying conditions necessary for health, as well as attitudes toward stigmatized populations.<sup>14</sup> Moreover, HRBAs training can increase awareness among staff of their ethical duties and the potential for their public health practice to impact the human rights of the populations they serve.<sup>15</sup> For example, after recognizing a lack of awareness of patients' rights and provider responsibilities, the Cambodian-German Social Health Protection Programme supported a policy framework to advance and promote patient rights along with operational guidelines, and codes of conduct and ethics.<sup>16</sup> Implemented through workshops for ministry officials, providers, and communities, this framework led to increased awareness of patients' rights, more respectful and professional treatment of patients, greater patient trust in providers, greater use of public clinics, and improved services in 90% of public health facilities. Other examples further demonstrate the potential power of increased awareness and knowledge of HRBAs among health care professionals to in-

crease the availability, accessibility, acceptability, and quality of health services.<sup>17</sup>

In 1993, the World Conference on Human Rights included “Education in Human Rights” as a priority area in the Vienna Declaration and Programme of Action, calling for governments to take an active role in promoting human rights education, and addressing the health profession as a special group for participation in education.<sup>18</sup> In 1998, the South African Truth and Reconciliation Commission recommended that training in knowledge, skills, and attitudes related to human rights must be a fundamental part of curricula for health professionals, as well as a part of their continuing education.<sup>19</sup> WHO, as well as the United Nations Office of the High Commissioner for Human Rights, also promotes training in HRBAs among health professionals, and have released guidance on the use of HRBAs to address specific health outcomes, including maternal morbidity and mortality, HIV/AIDS, and tobacco control.<sup>20</sup> Public health professionals have advocated for training programs and curricula specific to different types of health professionals and health outcomes—and at times they have been developed and implemented.<sup>21</sup> As of 2009, about one-third of schools of public health and medicine in the US provided some form of human rights education, with 22% offering required or elective courses.<sup>22</sup> As of 2019, 38 courses appear in an online database of academic courses on health and human rights as interest in the area has grown since the introduction of such courses.<sup>23</sup>

Operationalizing health objectives that are consistent with human rights is just one means of using HRBAs to promote health equity and sustainable health outcomes.<sup>24</sup> Training health professionals is a necessary step in the realization of this approach. Creating such a training first requires the identification of HRBAs knowledge, attitude, and skill objectives and competencies.<sup>25</sup> Potential knowledge competencies could include the identification of vulnerable groups or legislation pertaining to health; potential attitude competencies could include awareness of one’s own inherent prejudices or biases; and potential skill objectives could include the ability to recognize, report or respond to human rights viola-

tions.<sup>26</sup> Previous research has shown that appropriate training on HRBAs methods for health include: 1) experiential learning techniques which promote critical thinking about locally relevant health and human rights issues (case studies, debates, site visits, etc.); 2) trainers who have a range of domestic and international experiences in approaching health using a human rights framework; and 3) objectives and teaching methods with practical application to the current and future work of trainees.<sup>27</sup>

As the United States’ lead public health agency, the Centers for Disease Control and Prevention (CDC) conducts and supports health promotion, prevention, and preparedness activities with the goal of improving population health.<sup>28</sup> As a reflection of the CDC’s mission to preserve the health of US citizens, the agency engages in surveillance, population-based surveys, program monitoring and evaluation, laboratory science, and public health emergency response, among other activities.<sup>29</sup> With more than 12,000 employees working in over 120 countries, the CDC is made up of multi-disciplinary teams of public health advisors and analysts, laboratory scientists, epidemiologists, health scientists, behavioral scientists, economists, statisticians, and medical and nurse officers.<sup>30</sup> Given that disease and health conditions know no borders, the CDC employs locally employed (LE) staff in offices overseas.<sup>31</sup> LE staff are experienced public health professionals, as well as citizens or residents of the countries in which they work, offering a valuable contribution to CDC’s global health activities.<sup>32</sup>

Despite this, the CDC does not currently have a regular training curriculum on the use of HRBAs to health. There is a longstanding history of health and human rights-related interest and activities at the CDC; the late Jonathan Mann, considered the father of the health and human rights movement, spent his early career at the CDC. In 1997, the CDC’s National Center for HIV, STD, and TB Prevention (NCHSTP) created the first Health and Human Rights Workgroup (HHRW), though the group dissolved in 1998.<sup>33</sup> A new HHRW was founded in 2001, initially in the Epidemiology Program Office, and later expanded CDC-wide, becoming an officially recognized science workgroup in 2003.

HHRW includes more than 185 members representing every center, institute, and office (CIO) of the CDC. Through its work and collaborations, HHRW seeks to incorporate HRBAs into public health practice through seminars, workshops, and symposia. Despite these efforts, a formal training gap continues to exist among CDC staff.

Training needs assessments are an essential component of making an evidence-based determination of knowledge and skill gaps, desired educational components of a curriculum, and primarily, whether a formal training is appropriate for potential trainee populations.<sup>34</sup> Such assessments are particularly important for adult learners, as their work interests and skill needs should determine training objectives.<sup>35</sup> The purpose of this project was to conduct a HRBAs training needs assessment among CDC LE staff. The objectives of the needs assessment were to determine the following: 1) the desire for training in HRBAs to health; 2) the need for training in HRBAs to health; 3) the necessary objectives to include in HRBAs training; and 4) the types of trainers and appropriate methods to include in HRBAs training. These data will inform the development of a HRBAs training for LE staff; the goal of the training would be increased capacity in using HRBAs as part of ongoing CDC health promotion and disease prevention efforts.

## Methods

We conducted key informant interviews (KIIs) in June 2015 of staff members attending an annual CDC Center for Global Health regional training in Atlanta, Georgia; the target audience for the KIIs were supervisors of locally employed staff working in CDC country offices. We structured questions to assess HRBAs to health training needs among the key informants (KIs) as well as their staff. We also administered a web-based knowledge, attitudes, and practices (KAP) survey to CDC staff from June to December 2015.

### *Target population*

Locally employed (LE) staff are employees of CDC working in country office in locations outside of

the US; they are typically citizens or residents of the countries in which they work. This includes locations in sub-Saharan Africa, Southeast Asia, Latin America, and the Caribbean.<sup>36</sup> There are approximately 1,500 LE staff in more than 60 countries worldwide, many of whom liaise with key stakeholders such as the Ministry of Health in their country.<sup>37</sup> They work closely with the populations they serve, often focusing on populations vulnerable to health concerns.

### *Tools*

We conducted a literature review focused on HRBAs training, concepts, and methods. Informed by the literature review, we developed an original HRBAs to health KII guide; we also adapted existing survey instruments for use in quantitative data collection.<sup>38</sup> We designed the study tools in collaboration with members of the CDC's HHRW, and subject matter experts in public health, human rights, training/curriculum development, and adult education reviewed both instruments.

The semi-structured KII guide included ten open-ended questions. Domains for exploration included personal experiences in public health and HRBAs to health, as well as perceptions of LE staff experience with the same topics. Preferred training methods were a third domain of inquiry. The 35-question KAP survey included three parts. The first part collected demographic and work experience information, including gender identity, age, country of origin, race/ethnicity, education, position, and years working at CDC. The second part included items on HRBAs knowledge, attitudes, and practices. The third part consisted of five questions on preferred training methods, including educational methods (lecture, case study, problem solving), types of trainers (local/international public health experts, local/international human rights experts, local/international HRBAs experts), and public health topics (emergency preparedness and response, influenza, malaria).

### *Data collection procedures*

We conducted KIIs on June 9 and 10, 2015. We recruited LE staff in supervisory roles at



an annual regional training. KIs gave verbal consent to be interviewed and recorded. We conducted interviews until saturation.<sup>39</sup>

We distributed the KAP survey to staff via the internal CDC Global Health Community listserv—a list of all CDC staff who work in global health. One week later, we disseminated the KAP survey via the CDC Today Announcements, a listserv to which all CDC staff are subscribed. The KAP survey was open from September 1, 2015 to December 31, 2015. On October 28, 2015, we sent reminders through the same listservs. The KAP survey took approximately 10–15 minutes to complete.

### *Data analysis*

The KIIs were transcribed verbatim and coded in MAXQDA 11.<sup>40</sup>

We extracted KAP survey data from Survey Monkey into an Excel spreadsheet and imported the data into SAS 9.4 statistical software.<sup>41</sup> Although data were collected for all CDC staff, we only analyzed data for LE staff. We conducted univariate analyses to measure frequencies and percentages. We collapsed knowledge variables from a 4-point scale (“trained,” “have read about,” “have heard about,” and “no knowledge”) to a 3-point scale with the categories of “trained,” “limited knowledge,” and “no knowledge.”

### *Ethical considerations*

This project was reviewed in accordance with CDC human subjects review procedures and was determined to be a non-research activity. The Emory University Institutional Review Board also reviewed this project and found it to be exempt from human subject review. Nevertheless, ethical standards were maintained throughout the study process including informed consent and confidentiality.

## Results

### *Key informant interviews*

Eight staff members participated in the interviews, which lasted from 12 to 24 minutes. Three KIs were working in Asia and five in Africa. Seven worked in the Division of Global HIV/AIDS and

TB, and one KI worked in the Global Immunization Division. There were no apparent differences between responses from those working in Africa or Asia; informants from both regions expressing similar attitudes toward training, training needs, and training method preferences. Five themes emerged inductively from the KIIs: 1) human rights violations impact access to health services, 2) there is a lack of knowledge of HRBAs, 3) there is a need for HRBAs training, 4) there is a preference for interactive training methods, and 5) a combination of facilitator types is most desirable. All KIs were able to identify instances in their work where violations of human rights impacted health. Much of this surrounded discrimination experienced by vulnerable groups overseas, including sexual minorities, sex workers, injection drug users, criminals, and those living in remote areas. One KI elaborated upon the attitudes of people working in the health facilities for which he is responsible, paraphrasing such interactions in the following way:

*“Hey, this guy is gay, he’s got HIV, so why should we treat him? He’s suffering for his sins, so leave him alone. And we don’t even have enough to take care of people who are considered normal citizens. Why should we waste our money on this?” And we have to tell them that’s not the point. The issue is that they are humans. They have the right to health, and they are the ones that are affected. So we need to treat them.*

KIs were able to verbalize the ways in which a lack of human rights, specifically those related to discrimination, could lead to a lack of access to health services. However, when asked the extent of their knowledge in HRBAs, five of the eight informants answered with some version of “no idea” or “not much.” Two revealed a limited amount of knowledge, which they had gained through reading or partnering with human rights and advocacy groups. However, neither of these two felt they had “sufficient knowledge” to overcome service provision obstructions in the face of human rights violations, or to incorporate HRBAs into their health work. One KI articulated the knowledge level of most KIs:

*More and more, given the work that we do on HIV/AIDS with our local partners, we become aware of the areas, of arenas, where human rights clearly has a role in it, you know. But me personally, I have to admit that I've not always known what to do with that.*

All KIs expressed the feeling that their staff did not have knowledge in HRBAs. Informants also acknowledged that rights violations can interfere with the work of their staff in ways that neither informants nor their staff are equipped to address. One KI revealed, “They come back and talk to me, and there’s nothing I can do for them in some ways.” Regardless of their knowledge levels, all KIs verbalized a desire for training in HRBAs. KIs expressed the need for general knowledge in human rights in order to know what to look for, and to know what their responsibilities may be. Informants felt they were unable to ensure human rights if they didn’t have this knowledge. Some wanted the ability to communicate using human rights frameworks. They wanted to understand not only the language of human rights, but how to speak about and promote human rights in a non-confrontational manner with people of varying perspectives, including political leaders. One KI pointed to the need to evaluate programs in order to know that they are reaching all groups, including vulnerable groups. Others expressed the desire to know which entities and organizations to reach out to or direct problems. One KI explained the potential benefits of training on HRBAs:

*Well, I think it would, at the very least, awaken me to recognize where there may be insufficient human rights in a particular...in a sector where I am working at. It may awaken me to see where [there] are gaps and help me to develop the programs and the strategies to hopefully be able to bridge those gaps...and eventually some implementation of practice to respect people’s rights, to design systems in ways in which we do not victimize people because of their differences, because of their orientation, or whatever the case may be.*

Whether for themselves as leaders and advisors, or for their staff as implementers, KIs expressed a strong interest in HRBAs training.

Consistent with adult learning theory, all KIs expressed the need for interactive training methods.<sup>42</sup> They recommended case studies, problem solving, and role play—all of which allow for a hands-on learning experience. Informants wanted to share experiences and lessons as part of the interactive learning process.

Along with an interactive learning environment, KIs also wanted to leave with practical skills that they could apply to their work. As one informant expressed, “Adult learning is not the volume of information you pour in. It’s to make it more practical and what they can relate to and apply.”

Some KIs expressed interest in engagement with human rights actors themselves, as well as people who have experienced human rights abuses that have affected their health. Two informants also expressed the desire for the training to take place within their country. This would save resources for those coming from low-income areas, and allow facilitators “to actually see what we are dealing with; to see some of the challenges we are dealing with, some of the dynamics that we, I don’t know, whether they be power dynamics, whether they be dynamics that revolve around economics...some of the cultural realities.” Overall, KIs saw the value in having varied types of facilitators. They felt that international experts were the most equipped to offer best practices occurring in other settings, as well as a broader perspective on the concepts related to HRBAs. Two informants did stress, however, that there should not be a US-focus. KIs felt that local experts have more knowledge of the context and experience in the overseas setting. Local experts were seen as more important if there was a language barrier in a training audience with low English language proficiency.

#### *Knowledge, attitudes, and practices survey*

Of approximately 1,465 LE staff members, 104 took part in the KAP survey (7% response rate). Sixty-three percent (63%) of the respondents worked in Africa, 26% worked in Asia, and the remainder worked in Latin America and the Caribbean (LAC) (11%) (Table 1). A slight majority of respondents were female (56%) and ranged in age from 30 to 49 years

old (77%). Most of the respondents were not in a supervisory role (60%). The majority of respondents had advanced degrees, such as a bachelor's (30%), master's (39%), or doctoral degree (14%). Two-thirds (66%) had worked at CDC country offices for five years or less.

Less than 6% of LE staff respondents were trained on any of the six HRBAs knowledge indicators included in the KAP survey. No LE staff had any training on the Siracusa Principles; 14% had limited knowledge, and 86% had no knowledge. In all other categories, most LE staff reported having "limited knowledge," including the concept of progressive realization (64%) and the connection between international human rights treaties in relation to duties of public health professionals (65%). Most (80%) had limited knowledge of HRBAs for the protection of populations, and of the underlying determinants of health (82%). On using a HRBAs approach to health planning, implementation, and monitoring, 75% had limited knowledge (See Table 2).

We determined interest in a HRBAs training through two attitude indicators. Overall, 86% of

LE staff felt that public health could benefit from incorporating a HRBAs framework into programs, policies, and research. Additionally, 82% of LE staff felt that CDC should do more to address human rights issues in its programs, policies, and research. We asked respondents to consider their current skills in HRBAs to health. Overwhelmingly, respondents felt that they were unable to develop programs using HRBAs (90%). On the other hand, most LE staff felt that they were able to identify human rights violations with 53% of LE staff claiming to have this skill. Among the other HRBAs skills presented, 75% of LE staff did not know how to communicate human rights violations and 82% of LE staff did not know how to use data to promote health using HRBAs. Many (42%) respondents preferred a combination of training methods (lecture, case study, problem solving, workshop, webinar series). Overall, respondents preferred trainers who are experts in HRBAs to health as opposed to experts in public health or in human rights alone. Forty-nine percent (49%) of respondents preferred local HRBAs experts, while 55% preferred international HRBAs experts. Respondents also identified particular

TABLE 1. Demographic characteristics of CDC locally employed (LE) staff respondents, N=104

	Frequency N=104	Percentage (%)		Frequency N=104	Percentage (%)
<b>Gender</b>	<b>104</b>	<b>100</b>	<b>Supervisory Status</b>	103	99
Male	46	44	Non-supervisor	62	60
Female	58	56	Team leader	6	6
<b>Age</b>	<b>104</b>	<b>100</b>	Supervisor	24	23
26-29	4	4	Manager	11	11
30-39	41	39	<b>Education</b>	103	99
40-49	39	38	Some college or less	14	14
50-59	19	18	Associate's degree	2	2
60 or older	1	1	Bachelor's degree	31	30
<b>Location</b>	<b>100</b>	<b>96</b>	Master's degree	40	39
Africa	63	63	Doctoral degree	14	14
Asia	26	26	Other	2	2
Caribbean	4	4			
Latin America	7	7			
<b>Years at CDC</b>	<b>104</b>	<b>100</b>			
<1	19	18			
1-3	28	27			
4-5	22	21			
6-10	20	19			
11-14	10	10			
15-20	4	4			
>20	1	1			

content areas of interest. Most frequently, they had an interest in HIV/AIDS as a topic within a HRBAs training more than any other topic (54%). There was also a preference for training in Emergency Preparedness, with 42% of respondents indicating interest in this topic.

*Limitations*

There are important limitations to this study. We created the KAP survey instrument based on HRBA literature and feedback from experts in public health, human rights, training/curricu-

lum development, and adult education. We did not test the KAP survey for validity or reliability. Moreover, the KAP survey did not capture prioritization of human rights issues that respondents were particularly interested in. We wrote and conducted the KAP survey and KII in English, which may not have been the first language of the LE staff; however, all KII participants indicated their willingness to be interviewed in English. We used convenience sampling for both the KII and the KAP survey. There are likely systematic biases affecting the results of both the interviews and

TABLE 2. HRBAs knowledge needs among CDC locally employed (LE) staff respondents

Knowledge	All LE [# (%)]
<b>The concept of the progressive realization of the right to health and relevant obligations</b>	
<b>Total</b>	88 (missing=16) <sup>a</sup>
Trained	3 (3)
Limited knowledge	56 (64)
No knowledge	29 (33)
<b>The connection between international human rights treaties related to the duties of public health professionals</b>	
<b>Total</b>	88 (missing=16)
Trained	2 (2)
Limited knowledge	57 (65)
No knowledge	29 (33)
<b>The Siracusa Principles in relation to public health emergencies</b>	
<b>Total</b>	87 (missing=17)
Trained	0 (0)
Limited knowledge	12 (14)
No knowledge	75 (86)
<b>Health and human rights in the protection of the overall health of populations</b>	
<b>Total</b>	86 (missing=18)
Trained	5 (6)
Limited knowledge	69 (80)
No knowledge	12 (14)
<b>The right to health based on the underlying determinants of health, such as food, water, housing, and health environment</b>	
<b>Total</b>	87 (missing=17)
Trained	5 (6)
Limited knowledge	71 (82)
No knowledge	11 (13)
<b>Health and human rights approach to health planning, implementation, and monitoring</b>	
<b>Total</b>	88 (missing=16)
Trained	5 (6)
Limited knowledge	66 (75)
No knowledge	17 (19)

a. "Missing" refers to respondents who did not answer the question. All questions other than LE staff status were optional.

the KAP survey as a result of these non-probability sampling methods. In particular, those who participated in this study may be inherently different from those who did not participate. Since our sample selection likely does not accurately reflect the target population, the assessment is not generalizable to all CDC LE staff. We had a low response rate for the KAP survey, affecting the internal and external validity of our results. Despite these limitations to the quantitative data, the rich content of the KII—where saturation was reached—supports much of the KAP survey findings. Lessons learned may be helpful for addressing training needs of health professionals, including at other federal agencies. Seven of the eight KIs worked in the Division of Global HIV/AIDS and TB; over half of KAP survey respondents expressed interest in HIV/AIDS as a topic area of a HRBA to health training. While most CDC LE staff work on HIV/AIDS, our results may overemphasize an interest in this topic and miss the interests of staff working with other areas. While time has passed since these data were collected in 2015, no significant changes have taken place in terms of CDC efforts to address HRBAs to health learning needs, indicating that the data likely still hold true.

## Discussion

KIs felt that while human rights violations have affected processes and outcomes related to their work, neither they nor their staff had the capacity to address these violations. They responded definitively that their work and that of their staff would benefit from a HRBAs training. Even those KIs who did express having more exposure to HRBAs felt they needed a better understanding. Most KAP survey respondents reported a lack of HRBAs knowledge or skills and very few had received HRBAs-related training in their duties as public health professionals. The majority of respondents believed that public health and the CDC could benefit from incorporating HRBAs into programs, policies, and research. HRBAs training needs included being able to communicate human rights violations, promote human rights, and create programs which

uphold human rights for all. Respondents identified several needed skills, including the ability to a) develop and evaluate programs for rights-related impacts and b) use data to promote human rights.

The widespread lack of knowledge of the Siracusa Principles is another important finding. The Siracusa Principles specify conditions that public health professionals should consider before enacting rights restricting measures, as well as conditions that must be maintained in disease control and public health emergencies.<sup>43</sup> An understanding of these principles and other relevant human rights standards is instrumental to ensuring that restrictive public health intervention is justified, necessary, non-discriminatory, and the least restrictive possible to achieve the goal of curbing serious threats to the health of populations and individuals. KAP survey respondents noted Emergency Preparedness and Response as a preferred training topic area, reinforcing the need for training in the Siracusa Principles.

In terms of educational methods, KIs made abundantly clear the need for an interactive, cooperative learning environment. In this environment, trainees experience the use of hands-on activities such as case studies, problem solving, and role playing to build practical skills which staff members can apply to their work, and which fits their context and content area. They also encouraged the sharing of ideas and expertise among training participants. These preferences are consistent with Knowles' theory of andragogy, including principles of: participation, use of learner experiences, practical activities, and immediate applicability.<sup>44</sup> KAP survey respondents showed a preference for a combination of educational techniques.

Both KIs and KAP survey respondents preferred HRBAs to health experts versus experts in human rights or public health alone. KIs expressed an interest in local experts for their ability to provide context-specific knowledge and experience while international experts were believed to provide a broader perspective on ways to engage in HRBAs. To our knowledge, this is the first time that a needs assessment in this topic area has been conducted among this population. Other needs



assessments in HRBAs training have focused on other populations and some in specific contexts or human rights areas.<sup>45</sup> KIs vocalized the extent to which failures in human rights protections can affect their processes and outcomes, yet, as echoed by KAP survey respondents, there is a lack of capacity among CDC LE staff to address health related human rights concerns. Based on the strong appeals for a HRBAs training among both KIs and KAP survey respondents, as well as the evidence of limited knowledge in this area, we recommend the development and systematic implementation of a HRBAs training for CDC LE staff. This training has the potential to develop LE staff capacity for use of HRBAs as part of ongoing CDC health promotion and disease prevention efforts.

CDC leadership and academics can partner to develop HRBAs training for CDC employees based on the results of this needs assessment. The overall goals of such a training would include 1) filling HRBAs knowledge gaps by increasing knowledge of human rights standards, bodies, and mechanisms, and 2) filling HRBAs skill gaps by increasing competency in implementation of HRBAs in reporting, policy, and/or programmatic actions. Examples of knowledge competencies include identifying international human rights treaties and standards and examining how these are related to the duties of public health professionals, and interpreting the Siracusa Principles and applying their use in public health emergencies. Example skill competencies would include developing a program using a HRBA to health, conducting a human rights impact assessment for a proposed public health program, and evaluating a health program's impacts on human rights. Trainings would use case studies and other interactive methods that allow for information exchange and discussion of local context-based issues and needs. Case studies would cover health topics such as HIV/AIDS and Emergency Preparedness and Response. Moreover, both local and international HRBAs to health experts will be involved in the development and implementation of trainings in order to provide a combination of broad perspective and best

practices along with a context-specific focus. The primary function of this initial training would be to increase awareness of HRBAs among trainees; while increased awareness of HRBAs has been found to improve health practices and services, we acknowledge that information is necessary but not sufficient.<sup>46</sup> This training provides a starting position to begin the use of HRBAs to health among CDC LE staff. Further training would likely be necessary to ensure the effective application of HRBAs for the protection and promotion of human rights.

In collaboration with the CDC's Center for Global Health, we hope to pilot such a training at existing CDC regional trainings which occur quarterly across Asia, Africa, and the Americas. Regional trainings are primarily targeted towards LE staff working in various CDC country offices. Next steps to advance this effort include 1) a review of existing courses and curricula relevant to the LE audience; 2) the development of a HRBA to health syllabus and learning modules for CDC LE staff; 3) resource allocation to pilot and evaluate the HRBA training at CDC regional trainings; 4) adaptation to the curriculum based on evaluation feedback; and 5) systematic rollout and scale-up of the HRBA training if proven successful.

## Conclusion

The objectives of the needs assessment were to determine the following: 1) the desire for training in HRBAs to health, 2) the need for training in HRBAs to health, 3) the necessary objectives to include in HRBAs training, and 4) the types of trainers and appropriate methods to include in HRBAs training. Based on the combined results of the KII and KAP survey, we determined that CDC LE staff desire HRBAs training in order to benefit their work as health professionals. There are also HRBAs knowledge and skill gaps which indicate the need for training. Therefore, we recommend the creation and implementation of HRBAs training for LE staff. Training topics should include HIV/AIDS, Emergency Preparedness and Response, and potentially others. The training of LE staff

should utilize a combination of interactive, cooperative learning measures, and a combination of local and international HHR experts. Advancing these efforts contributes towards increased health workforce capacity for the use of HRBAs as part of ongoing CDC health promotion and disease prevention efforts.

## References

1. WHO, A human rights based approach to health. Available at [https://www.who.int/hhr/news/hrba\\_to\\_health2.pdf](https://www.who.int/hhr/news/hrba_to_health2.pdf).
2. J. M. Mann, L. Gostin, S. Gruskin et al., "Health and human rights," *Health and Human Rights* (1994), 6-23.
3. J. Mann, "Health and human rights: If not now, when?," *Health and Human Rights* (1997), 113-120.
4. Siracusa principles on the limitation and derogation provisions in the international covenant on civil and political rights, E/CN.4/1985/4 (1985). Available at <https://www.refworld.org/docid/4672bc122.html>.
5. WHO, International health regulations (2005). Available at <https://www.who.int/ihr/publications/9789241580496/en/>.
6. E. Beracochea, C. Weinstein, and D. Evans, *Rights-based approaches to public health*, (Springer Publishing Company, 2010).
7. WHO, A human rights based approach to health. Available at [https://www.who.int/hhr/news/hrba\\_to\\_health2.pdf](https://www.who.int/hhr/news/hrba_to_health2.pdf).
8. General comment no. 14: The right to the highest attainable standard of health, E/C.12/2000/4 (2000). Available at <https://www.refworld.org/docid/4538838do.html>.
9. P. Braveman and S. Gruskin, "Poverty, equity, human rights and health," *Bulletin of the World Health Organization* 81/7 (2003), 539-545.
10. Fact sheet no. 31: The right to health 31 (2008). Available at <https://www.refworld.org/docid/48625a742.html>.
11. General comment 14, the right to the highest attainable standard of health, E/C.12/2000/4 (2000). Available at <https://www.refworld.org/docid/4538838do.html>.
12. Braveman (2003, See note 9).
13. J. M. Mann, L. Gostin, S. Gruskin et al., "Health and human rights," *Health and Human Rights* (1994), 6-23.
14. WHO, Human rights and health. Available at <https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health>.
15. S. Glowa-Kollisch, J. Graves, N. Dickey et al., "Data-driven human rights: Using dual loyalty trainings to promote the care of vulnerable patients in jail," *Health Human Rights* 17/1 (2015), E124-E35.
16. T. Silberhorn, "Germany's experience in supporting and implementing human rights-based approaches to health, plus challenges and successes in demonstrating impact on health outcomes," *Health and Human Rights* 17/2 (2015), 21-29.
17. M.-L. Escobar, L. Cubillos, and R. Iunes, "Looking for evidence of the impact of introducing a human rights-based approach in health: The saluderecho experience," *Health & Human Rights: An International Journal* 17/2 (2015).
18. Vienna declaration and programme of action, A/CONF. 157/23 (1993). Available at <https://www.refworld.org/docid/3ae6b39ec.html>.
19. TRC, "South Africa Truth and Reconciliation Commission Report: Volume 4, chapter 5. Institutional hearings: The health sector," (1998), 109-164.
20. Technical guidance on the application of a human rights-based approach to the implementation of policies and programmes to reduce preventable maternal morbidity and mortality, (2012). Available at [https://www2.ohchr.org/english/issues/women/docs/A.HRC.21.22\\_en.pdf](https://www2.ohchr.org/english/issues/women/docs/A.HRC.21.22_en.pdf).
21. P. Chastonay, A. M. Klohn, V. Zesiger et al., "Developing a health and human rights training program for french speaking africa: Lessons learned, from needs assessment to a pilot program," *BMC International Health and Human Rights* 9/1 (2009), 19.
22. L. E. Cotter, J. Chevrier, W. N. El-Nachef et al., "Health and human rights education in us schools of medicine and public health: Current status and future challenges," *PLoS One* 4/3 (2009), e4916.
23. USC, Health & human rights syllabi database. Available at <http://apruglobalhealth.org/hhrsyllabi/>.
24. L. London, "What is a human-rights based approach to health and does it matter?," *Health and Human Rights* (2008), 65-80.
25. J. Brown, "Training needs assessment: A must for developing an effective training program," *Public Personnel Management* 31/4 (2002), 569-578.
26. L. London and L. Baldwin-Ragaven, "Human rights and health: Challenges for training nurses in South Africa," *Curationis* 31/1 (2008), 5-18.
27. V. Iacopino, "Teaching human rights in graduate health education," *Health and Human Rights: the Educational Challenge. Boston: François-Xavier Bagnoud Center for Health and Human Rights* (2002), 21-42.
28. CDC, CDC at-a-glance. Available at <https://www.cdc.gov/about/facts/cdcastfacts/cdcastfacts.html>.
29. P. Farmer, "Pathologies of power: Rethinking health and human rights," *American Journal of Public Health* 89/10 (1999), 1486-1496.
30. CDC, CDC at-a-glance. Available at <https://www.cdc.gov/about/facts/cdcastfacts/cdcastfacts.html>.
31. DHHS, Department of health and human services secretary's locally employed staff of the year award. Available at <https://www.cdcfoundation.org/blog-entry/compassion-fund-global-health-workers>.



32. E. Mitchell, CDC foundation's compassion fund for global health workers. Available at <https://www.cdcfoundation.org/blog-entry/compassion-fund-global-health-workers>.

33. N. Nijim, "The birth of the health and human rights workgroup (HHRW)," *HHRW Bulletin* 1/1 (2007).

34. J. Brown, "Training needs assessment: A must for developing an effective training program," *Public Personnel Management* 31/4 (2002), 569-578.

35. S. B. Merriam, "Andragogy and self-directed learning: Pillars of adult learning theory," *New directions for adult and continuing education* 2001/89 (2001), 3-14.

36. E. Mitchell, CDC foundation's compassion fund for global health workers. Available at <https://www.cdcfoundation.org/blog-entry/compassion-fund-global-health-workers>.

37. NIH, "Cdc views global health as key priority," *Fogarty International Center* 13/4 (2014), ; ([internal communication]).

38. P. Chastonay, A. M. Klohn, V. Zesiger et al., "Developing a health and human rights training program for french speaking africa: Lessons learned, from needs assessment to a pilot program," *BMC International Health and Human Rights* 9/1 (2009), 19.

39. M. Hennink, I. Hutter, and A. Bailey, *Qualitative research methods*, (Sage, 2010).

40. VERBI Software. (2015). MAXQDA. (11) Berlin, Germany.

41. SAS Institute Inc. (2011). SAS intitute inc. (9.4) Cary, NC.

42. M. S. Knowles, *The making of an adult educator: An autobiographical journey*, (Jossey-Bass Inc Pub, 1989).

43. Siracusa principles on the limitation and derogation provisions in the international covenant on civil and political rights, u.N. Doc. E/cn.4/1985/4, annex, (1985). Available at <https://www.refworld.org/docid/4672bc122.html>.

44. M. S. Knowles, *The making of an adult educator: An autobiographical journey*, (Jossey-Bass Inc Pub, 1989).

45. R. Asgary, "Graduate public health training in health-care of refugee asylum seekers and clinical human rights: Evaluation of an innovative curriculum," *International Journal of Public Health* 61/3 (2016), 279-287.

46. T. Silberhorn, "Germany's experience in supporting and implementing human rights-based approaches to health, plus challenges and successes in demonstrating impact on health outcomes," *Health and Human Rights* 17/2 (2015), 21-29.

## COMMENTARY

# Institutionalizing Ethical Review in Global Health Practice: A Modest Proposal

DAVID ROSS

Assuring basic human rights for all, seeking social justice, and the ethical implementation of policies to make these goals a reality begins with inspired leaders who have the courage and imagination to challenge established power. Once the social change process has begun, then governance structures and organizational processes must be established if that change is to be made permanent. As countries move toward health equity, this march must be guided by standards of practice that promise ethical treatment of those whose lives we seek to improve. To achieve health equity, Lawrence Gostin et al. call for the World Health Organization's adoption of a global health framework that is capable of ensuring a well-functioning health system, a full range of public health services, and economic and social conditions conducive to good health.<sup>1</sup> In my role as CEO of the Task Force for Global Health, I am both inspired and challenged by the need to fully integrate systematic ethical review into our organizational structure and programmatic practice. Here, I describe my vision for how ethics can more meaningfully be implemented in global health.

Realizing the vision of the Universal Declaration of Human Rights requires ongoing efforts to make it relevant across many cultural traditions and countries' diverse governing structures. In our search for health equity, it seems clear that countries need a formal framework to guide the creation and maintenance of essential personal and population-based services. In addition, we must also assure that the services provided by this framework guarantee the ethical treatment of all people. Achieving health equity requires both structure and process. Today, organizations such as the Task Force for Global Health entrust partner nongovernmental organizations and their networks of community health workers and other providers to deliver medicines, nutritional supplements, and other interventions. The populations that these organizations serve have little recourse to redress if the services provided or the outcomes experienced are inadequate or harmful as a result of the work of these organizations. Thus, we must ask: Does the large global health enterprise need an ethics framework that creates jointly held accountability among global health funders, program implementers, and national governments?

The clinical research enterprise has informed consent and institutional review boards to ensure that well-intended researchers make explicit to all affected how they will balance the risk of harm against benefit. Can global health programs learn from the research enterprise by implementing a means by which those affected, those providing direct service, and those promoting social and health benefits can be assured that

---

DAVID ROSS is president and CEO of the Task Force for Global Health, Decatur, USA.

Please address correspondence to the author. Email: [dross@taskforce.org](mailto:dross@taskforce.org).

Competing interests: None declared.

Copyright © 2019 Ross. This is an open access article distributed under the terms of Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original authors and source are credited.

they have considered at the outset and throughout the work that important ethical lapses have not occurred? The answer to these questions seems obvious. By failing to make explicit how global health programs protect those we seek to benefit, we fail to protect human rights. When we fail to implement ethical reviews by failing to monitor programs for ethical challenges, we risk violating the rights of those we serve.

The three-day symposium on global health ethics held at Agnes Scott College in April 2018 provided numerous examples of ethical challenges confronting the implementation of global health work. The articles in this special section address a wide range of constructs that should guide how we consider ethical issues. All of these issues speak to the need for a routine or standard way in which global health funders, program implementers, and country participants consider, adjudicate, and resolve ethical challenges throughout the life cycle of global health programs.

### A modest proposal

Today's expected practice for proposals submitted to any large global health funder requires that the proposals include clearly stated governance structures, project plans, program management plans, budget controls, and plans for the monitoring and evaluation of processes and outcomes. As demonstrated in the articles in this special section, an emerging body of evidence now points toward adding ethics review as a new dimension to the definition of well-run and -managed global health programs.

Best practice today suggests that when one is creating a new program, the program should have a charter. A comprehensive program or project charter includes a complete statement of purpose (i.e., the goals and impact of a successful project), an evaluation framework showing the metrics of success (i.e., process and outcome measures), a governance structure (i.e., who makes which decisions), a detailed project plan, a communications plan (i.e., which audiences need to know what and when), and a budget and budget narrative. Each

of these components is informed by a body of peer-reviewed and practice-based evidence and is supported by professionally trained practitioners in that discipline. For example, professional project managers bring with them a discipline for coordinating interdependent activities over time to enable a smoothly functioning program that achieves its goals on time and within budget. Similarly, evaluation scientists develop feasible and meaningful measures that guide investment in, management of, and interpretation of program work.

A formalized ethics review and monitoring needs to be added and supported by trained global health ethicists. By incorporating such a component into programming, global health practitioners can assure that the noble aspirations of their programs do the good they are intended to do. By incorporating ethics review and monitoring as one of the core global health practice disciplines, we give voice to those we seek to help while also offering assurance to the helpers that they will do no harm. There is much work to be done to establish workable processes through which meaningful ethical review of global health programs can be conducted without hampering creativity in our programmatic solutions to global health problems, where we must often adapt quickly to changing conditions or crises on the ground. However, it is only through initiating this process that we will be able to develop a robust evidence base for ethical practice in the implementation of the right to health.

The time has come to define the components of a global health ethics review and to mandate that review as one of the essential elements demanded of program implementers. All parties—program funders, those who receive our services, those who govern health in countries, and those who implement programs—need to view ethics as one of the essential components of their program charter. Just as the right to health has been discussed and debated by many, the process of including ethics in official project funding awards would spark deeper, meaningful discussion from various viewpoints about what is ethical.

## Getting started

At the Task Force for Global Health, we have created a Focus Area on Compassion and Ethics (FACE) to serve as an organizational hub for our thinking about the ethical implementation of our programs, as well as the broader issue of working ethically toward the goal of health as a human right. By formalizing FACE as one component of strong program management, we encourage our program leaders to be aware of ethical dilemmas, ask thorny ethical questions, and seek well-reasoned solutions. Functioning ethically as an organization requires a workforce educated in essential ethical principles. We guide ethical decision making through institutional processes that are measured as part of routine field operational data gathering to assure accountability. We need to see other global health organizations embrace procedural ethics as a means of guaranteeing that we walk the talk of seeking social justice and universal human rights.

## References

1. L. O. Gostin, E. A. Friedman, K. Buse, et al., "Towards a framework convention on global health," *Bulletin of the World Health Organization* 91 (2013), pp. 790–793.





# Ethics of Global Health Photography: A Focus on Being More Human

AUBREY P. GRAHAM, JAMES V. LAVERY, AND ROBERT COOK-DEEGAN

## Abstract

This article explores the relationship between ethics and the production of global health photographic images. Through the text, we emphasize the need for greater awareness of potential ethical pitfalls, not just in relationship to the finished product of the image but also throughout the full photographic process. In order to do so, we present and explore three vignettes detailing our personal global health photographic experiences. Using these examples of the process of photographic production, we argue that the ethical emphasis needs to fall as much on the way of making and circulating the images as on the resulting images and their content. In showing that ethics starts long before the decision to publish a photograph, we engage global health photography as a relationship built of unequal power dynamics, where agency is held (albeit lopsidedly) by all of those around the camera—the subject, the photographer, and the bystanders or actors who exist beyond the photograph’s composition. By following the concept of “encouraging people to do what is best given certain circumstances and constraints,” we as photographers and global health workers advocate for a more fully human interaction through conscious, careful global health visual policy and humane photographic deliberation.<sup>1</sup>

---

AUBREY GRAHAM is the Interdisciplinary Postdoctoral Teaching Fellow at the Institute for the Liberal Arts at Emory University, Atlanta, USA, and a freelance photographer.

JAMES V. LAVERY is the Conrad N. Hilton Chair in Global Health Ethics, professor in the Hubert Department of Global Health in the Rollins School of Public Health, and faculty member of the Center for Ethics, Emory University, Atlanta, USA.

ROBERT COOK-DEEGAN is a professor at the School for the Future of Innovation in Society at Arizona State University, USA.

Please address correspondence to Aubrey Graham. Email: [aubrey.graham@emory.edu](mailto:aubrey.graham@emory.edu).

Competing interests: None declared.

Copyright © 2019 Graham, Lavery, and Cook-Deegan. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted noncommercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

## Introduction

For decades, photographs have played a central role in the documentation of global health issues, outbreaks, crises, and successes. While expected as part of the visual economy of global health research and representation, photographic images nonetheless hold the power to leave a mark on both the individuals photographed and those who take the photos. In this article, we explore the ethics of global health photography by addressing poignant instances of image production that are grounded in our personal experiences as photographers, as well as academics and practitioners. Further, we aim to show the need for greater awareness of ethical pitfalls, not just in the image but throughout the photographic process and its uses.

Using detailed vignettes, we address our personal experiences with the ethical dilemmas brought home when creating images in global health and human rights fieldwork. While we produced our respective photographs in different crises at different times, each retelling elicits insights borne of hindsight. With awareness comes a desire to better understand both the ethical quandaries of the images and our personal, affective responses to the photographic situations. In our vignettes, we raise questions that stretch beyond the subject matter of the image itself. Instead of leveling our critique only at such representational content—the signifiers and their meanings captured within the frame of the image—we also raise ethical concerns about the *process* of global health photographic production and its uses. Engaging these vignettes in the order they occurred, we address our actions and the relationships implicated within photographic creation, publication, and dissemination. In so doing, we advocate for global health visual policy and conscious photographic deliberation for a more fully human interaction beginning before the shutter snaps and carrying forward throughout the life of the image.

### *Global health photography*

We define global health photography as taking and using images in the service of a global health program or initiative. Images may range from

professional photographs created by contracted photographers to cell phone images crafted by agency staff and visitors. In this article, we discuss photographs produced in the context of chemical weapons use, displacement, genocide, conflict, and maternal health. Our images, like many human rights and humanitarian photographs, were not created haphazardly. Rather, they follow a system that employs the image as both evidence of reality on the ground and a means of organizational marketing.<sup>2</sup> Such images are not only persuasive beyond words, but are used to supplement words, often to elicit emotional reactions. Such photographs populate newsletters, websites, news stories, social media, communication campaigns, letters to donors, political advocacy, and public presentations. In each type of communication, global health images fulfill their roles through the power to multitask, merging emotional resonance and documentary accounting; they graphically witness the nature and scope of human needs, account for money spent and work completed, and play central roles in crafting campaigns for support, targeting the government, donors, or the general public.<sup>3</sup>

Images produced in the service of global health and human rights are guided by an often implicit visual economy. Deborah Poole describes the “visual economy” as the way images are understood in relation to the relevant “social relations, inequalities, power relations and politics,” which require attention not just to a photograph’s content but also to the process of its production, circulation, and consumption of images.<sup>4</sup> She argues that images function as cascades of flows that, like the economy, follow a system shaped by the globally implicated exchange values and visual economy of the image and its genre.<sup>5</sup> Thus, as images are created, circulated, and consumed, they get incorporated into the international power dynamics embodied in the relationships of photographer, subject, consumer, and publisher.

Within the economy of global health imagery, the benchmark currency is a “good” or “necessary” photograph—one that is both legible and functional for the organization. There is often an expectation that surrounds both the represen-

tational content and the expected *work* the images will perform. Poole shows that while such images rarely come with explicit viewing instructions, the photographer's act of creating the image responds to, and conforms to, all of the previous circulations and consumptions of similar images—a learned awareness of the moment and of what makes a potential photograph “valuable” and therefore worth capturing.<sup>6</sup>

In large part, since the 1970s, “valuable” images within the visual economy of humanitarianism and global health have been those that are able to incite action through moral outrage or, more recently, through a shared sense of empowerment. In particular, the notable visual tropes of skeletal adults, fly-eyed children, white saviors, and the dead haunted publications from the late 20th century aiming to raise the compassion, awareness, and funds necessary for intervention.<sup>7</sup> As these photographs circulated in international news media and advocacy campaigns for nongovernmental organizations (NGOs), they also drew criticism for concerning how they objectify, demean, and “further reduce the powerlessness” of the featured individuals and groups.<sup>8</sup> Kevin Carter's 1994 Pulitzer Prize-winning photograph of a Sudanese child and a lurking vulture presents a quintessential example. Was the trade-off between momentary objectification and the potential of further funding, attention, and action a worthy one? Arthur Kleinman and Joan Kleinman provide a related call to action, noting:

*We will have to engage the more ominous aspects of globalization, such as the commercialization of suffering, the commodification of experiences of atrocity and abuse, and the pornographic uses of degradation ... the first issue would seem to be to develop historical, ethnographic, and narrative studies that provide a more powerful understanding of the cultural processes through which the global regime of disordered capitalism alters the connections between collective experience and subjectivity.*<sup>9</sup>

This article aims to do just that. The ethical challenges that motivate these visual critiques share much in common with the ethical challenges that

have fueled the growing emphasis on participatory practices, community and stakeholder engagement, and co-production of knowledge in global health.<sup>10</sup> Like photography, these approaches and emphasis on ethical action are not new, though they do represent challenges to the status quo. Within global health, the weight placed on ethics has long been understood to be a key factor in not only what research is conducted but also how it is carried out. The 1979 Belmont Report, National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, for instance, provides an early example of essential guidelines surrounding the need for beneficence, respect, and justice in global health research. Over the past four decades, ethics has come to occupy a central place within global health as the collective consciousness is raised about the presumptuousness, disregard, unfair partnerships, exploitation of power differences, and even human rights violations that continue to occur in the context of global health programs.

Returning to the photographs—while the critiques are excellent at drawing attention to the photographers' composition, little exists in print about the actions, decisions, and negotiations that lead to the production of the global health images, ethically questionable or not. We hope that by focusing retrospectively on the actions, thoughts, and insight from photographer-practitioners in situations of uncertain ethical action, we can incite better understanding of how ethics are implicated throughout the process of creating images. In other words, by tying the growing importance of global health ethics into the existing critiques and ethical concerns about photography produced in the practice of humanitarianism and global health, we argue that some critical self-reflection on the practice of photography might serve as an excellent point of departure for a broader engagement with these problems in global health programs.

### Photographic retrospectives

In the following vignettes, we engage three distinctive images and their respective social politics and ethics. Our first two retellings (vignettes by

Cook-Deegan and Lavery, respectively) function to outline ethical challenges implicit within the production phase of the visual economy of global health images. Through the third vignette (by Graham), we grapple with similar visual quandaries and logistical challenges, but also work to produce a path forward toward increasingly ethically aware photography. In each of the vignettes, we look back at photographic production and the relationships that the act of photography forges through each snap of the shutter.

*Pictures and poison gas: Vignette by Robert Cook-Deegan*

Despite years of work in health and human rights, I had never heard of the Kurds until September 1988, when Jonathan Fine and Susannah Sirkin called from Physicians for Human Rights (PHR) in Cambridge, Massachusetts. After a month of trying to get a team into Iran, they had decided to instead send a team to southeastern Turkey to investigate the alleged chemical weapon attacks that had occurred the previous month against the Kurds of northern Iraq. The world knew the attacks provoked a flood of refugees from Iraq into Iran and Turkey. Refugees were now in camps along Turkey's borders with Syria and Iraq. The advantage of Turkey? No visa was required.

That phone call launched a frenzy of research. I was employed at the congressional Office of Technology Assessment, with full access to the resources of the Library of Congress and a Rolodex of contacts in national organizations and federal offices. I spent that weekend reading *The Poisonous Cloud*, a history of chemical weapons by Fritz Haber's son, and collected the 252 reports from the United Nations (UN) about chemical weapons use in the Iran-Iraq War that had ended in 1988.<sup>11</sup> That war consumed eight horrible years that left well-nigh a million dead and severely wounded, but very little change in the national borders or political balance of power. It was a stupid, wasted war that entailed the most extensive use of chemical weapons since World War I. It was the most flagrant violation of the 1925 Geneva Protocol prohibiting the use of chemical weapons since the protocol entered into

force in 1928.

The UN reports left no doubt that chemical weapons were used.<sup>12</sup> The question in the fall of 1988 was whether and how Saddam Hussein's Iraqi government used chemical weapons against its own civilian Kurdish population. The March 1988 chemical attack on the city of Halabja drew international attention. The attacks against the Kurds in northern Iraq five months later, and the flood of refugees into Iran and Turkey, produced a flurry of news reports, but the governments of Iraq and Turkey denied permission for a UN ground crew to investigate, and despite extensive intelligence corroborating the attacks (made apparent years later), the major powers—including the United States—equivocated about whether the attacks had even occurred.<sup>13</sup>

**PHR mission to southeast Turkey.** Enter PHR to fill this gap. A team of three—Asfandiar Shukri, a Kurdish-speaking Detroit physician; Howard Hu, then a young faculty member at the Harvard Medical School; and I—assembled various materials in preparation for a 10-day investigative field mission. One of the most useful documents was a how-to report from the government of Canada, entitled *Handbook for the Investigation of Allegations of the Use of Chemical or Biological Weapons*.<sup>14</sup> It warned that direct access to the sites of attack might be blocked. It included a questionnaire to elicit details to document an attack and identify the chemical agents involved. Dr. Shukri translated this questionnaire into Kurdish, and we took more than 100 copies with us.

After preliminary meetings, we gained access to two refugee camps near Diyarbakir: one camp in Mardin, along the Syrian border, and another just outside Diyarbakir itself. Turkish authorities running the camps introduced us to Kurdish leaders in the camps. We explained that we were American doctors who wanted to know the health status of those in the camps. Dr. Shukri conducted interviews inside one large tent, while camp residents filled out questionnaires. I was the videographer for those interviews, while Dr. Hu circulated throughout the camp doing field epidemiology.

The questionnaires proved to be important sources of evidence, because we could triangulate responses from residents of the two camps who had not had contact with one another but who originated from the same villages, which would allow us to independently corroborate accounts. We also took photos of healing chemical burns. But the most useful artifacts of the camp visits—the evidence that proved most persuasive—were pictures of the refugees, especially the children and women, and videotapes of Dr. Shukri's interviews. The persuasive power of women and children was not merely emotive but also evidentiary: they were not combatants, but civilians caught in poison gas attacks.

The testimony of one eight-year-old girl, in particular, was utterly compelling. She had been silent for weeks in the camp, in shock from having lost both parents and several siblings to the poison gas attacks. She had been out tending the sheep a kilometer uphill from her home when bombs fell near her house, killing half her family. She returned to find them dying and turning color, with froth leaking from their mouths. She was restrained from touching them by relatives, who then led her and other surviving children on a several-day trek across the mountains into Turkey. Dr. Shukri somehow made her feel safe enough to tell her story. She did so in a soft, calm voice, often quavering; there was not a dry eye among the 20-some listeners in the tent. Indeed, the video footage was shaky, as I trembled from uncontrollable emotion.

We prepared a preliminary report of our findings that was released before we left Ankara and worked on a more complete draft on the flights to Frankfurt and Washington. Upon our arrival, we briefed members of the House Appropriations Committee and officials in the State Department, and held several press briefings. We wrote our report, *Winds of Death*, in November and December. The draft report was sent for external expert review in January and the final report released in early February; a summary was published in the *Journal of the American Medical Association*.<sup>15</sup> Over the next six months, I testified a half-dozen times in the House and Senate, as our evidence was deemed relevant to the 1989 Iraqi sanctions bills that passed

overwhelmingly in Congress but were ultimately pocket-vetoed by President George Herbert Walker Bush because he did not want the precedent of Congress intervening in foreign policy.<sup>16</sup> This was one of several diplomatic missteps that the US government made, which Saddam Hussein interpreted as a green light to invade Kuwait in August 1990, which in turn led to the First Gulf War of 1991 (and another PHR mission to southeast Turkey and northern Iraq in April 1991).<sup>17</sup> We also gave many presentations to NGOs and government organizations—including human rights organizations, foreign policy groups, and those concerned about the use of chemical and biological weapons. Those briefings featured our video and photographic evidence, which was the most compelling aspect of our story and much more gripping than the quantitative data. The eight-year-old girl was literally our poster child for an advocacy campaign.

We did take precautions to protect our materials. While in the field, I kept the videotapes on my body at all times. We knew that if we were detained while I was carrying the tapes, we would be giving authorities the most damning evidence and would lose our most valuable material. We surmised, however, that the authorities were unlikely to escalate to the point of detaining and searching us. We were quite careful to protect the completed surveys from prying eyes. I left a blank set of surveys in my briefcase in our hotel, deliberately leaving my briefcase in our locked hotel room. My briefcase was opened while we were at dinner, as was Dr. Shukri's suitcase—which held the video camera in which we had placed blank tapes (see Hall-Clifford and Cook-Deegan in this volume). We thus confirmed that someone was curious about our activities. We redoubled our attention to confidentiality. But once we returned to the United States, we encouraged the broad use of our materials. Our purpose was, after all, to get the word out, to confirm the poison gas attacks against civilians in northern Iraq, and to dispel doubts that such an attack had happened at all.

We thought through our use of photos and videos mainly in retrospect. The visual materials were very widely distributed and could have led



authorities back to the camp residents whom we interviewed. While of relatively low quality, excerpts of our videotapes were used by US broadcast and cable networks because there were no better sources. Longer excerpts were incorporated into a UK documentary, *Winds of Death*, on UK Channel 4, where they were widely viewed.<sup>18</sup> A copy of our report was found in the possession of an Iraqi journalist who ventured into Iraq. He was arrested and executed in the prelude to the 1991 Gulf War, and we learned of his death from UK journalists. The low-resolution photos in our report were thus clearly in possession of Iraqi authorities. In looking back, we realized we had endangered those we photographed and videotaped. The story could have had an unhappy ending.

One of the striking features of this mission is how much effort was put into preparing to gather the epidemiological and survey data, as well as getting consent to gather survey data, and how comparatively little we thought about the photographs and videotapes. And yet those proved to be the most useful results of our work, and the sources of greatest risk to those we interviewed. The photographs in the PHR report were probably not identifiable, due to low-quality reproduction in those days of primitive laser printers and low-budget PHR reports. However, we used much higher-resolution photographs in public presentations to large audiences, including open fora in Washington, DC, that were no doubt attended by officials of the offending powers. There were well over 100 people present in one Senate hearing presided over by Senators Edward Kennedy and Jesse Helms, for example. We made no attempt to obscure the identities of those photographed. Through those photographs, people we spoke to in the camps were identifiable. While we had explained why we were in the camp, and it was obvious we were taking photos and recording videotape, we only later realized that we could have put those we interviewed in real danger. They were in camps for many more months, under the thumb of a demonstrably racist regional governor who had ordered the torture and death of hundreds of Kurds in Diyarbakir, as documented by Amnesty International.<sup>19</sup> While the interviewees and their families

were aware of what we were doing in the camp, they simply could not have understood or anticipated the worldwide distribution of their faces and stories, any more than Pashtun refugee Sharbat Gula could have known that she would become one of the most recognized faces in the history of photography through Steve McCurry's cover photo for *National Geographic* in June 1985.<sup>20</sup> Some of those in the camps might still have consented in the face of personal risk; but we put them and others at risk without their fully informed consent—not because we were unaware of the concept, but because we did not apply the precautions we took for written surveys to photographs and video interviews. One of our team remains in contact with the family we interviewed, and we know they are safe and reside in a part of Iraq that the government cannot readily touch, but we did not think through those risks in advance.

The power of the child's photograph was directly attributable to her beauty and obvious innocence. We deliberately used it for emotive effect, and with no apologies for that effect. We were accurately documenting the story of a heinous crime via a first-person witness. Telling her story was voluntary, and the telling was greeted with relief by her family, a sign of psychological improvement after weeks of shock. But we could easily have mitigated the risks by being more selective in our audiences (for example, using high-resolution photographs only in personal briefings with members and staff, but not public presentations), and we could have ensured that the family was safe before using the photos publicly through the indirect channels of communication that persisted after our return. We recognized this mortifying lapse only in retrospect. The main lesson was to think through use of photos and videos as explicitly as other more traditional empirical evidence.

*The primordial discourse: Vignette by James V. Lavery*

The photograph that has prompted this narrative was the very first photograph I ever took in the context of a global health program, in this case a Médecins Sans Frontières (MSF) mission in Rwan-

da about nine months before the 1994 genocide. As the inaugural editor of *Outskirts*, the newsletter for the newly created MSF Canada, I was in Rwanda with Ben Chapman, MSF Canada's program manager, to visit Pierre La Plante, a Canadian nurse who was leading an MSF mission to support Rwandan populations that had been driven south into various makeshift camps by conflict around the northern border with Uganda. We had arrived in Kigali, the Rwandan capital, on an overnight flight from Paris the previous day and had met the MSF team and settled into our rooms in the house that MSF was renting in the city. This trip was my first to sub-Saharan Africa. I had travelled in South Asia and North Africa previously and was an enthusiastic amateur photographer.

As the newest member of the MSF family at the time, MSF Canada was finding its way under the guidance of MSF Holland, our MSF parent-sponsor. As an inexperienced editor, I was beginning to learn about the importance of the MSF national newsletter as a fundraising vehicle, as a means of informing donors about how their contributions were being used, and as a way to serve one of the core elements of MSF's mission: *témoignage*, or bearing witness to the humanitarian crises that are MSF's *raison d'être*. With these considerations front of mind, I was anxious to get into the field to begin my education about how MSF missions work and attempt to explain this to our Canadian readers through stories and the transportational power of photographs.

I was up early the following morning and pulled my cameras out onto the kitchen table. My Nikon F3 was already loaded with a roll of Fujichrome 100 slide film, and I loaded a new roll of Kodak Ektachrome 160 slide film into my Nikon FM2. I checked and cleaned my lenses, packed my camera bag and my notebook—the old paper kind—and was ready to go. We left for the field at 8:00 a.m. in the MSF Toyota Land Cruiser with our driver, Jean, who was later killed in the massacre. It was raining lightly and the sky was heavy in a state somewhere between mist and fog. I sat in the rear right-hand seat beside Ben and directly behind Pierre. We were headed to a large camp of about

40,000 displaced people about 90 minutes north of Kigali. But Pierre announced that he first had to make a quick stop at a smaller camp about 20 minutes outside the capital to relay a message to one of the camp coordinators.

The camp was easily accessible from the main road, and we pulled into a flat, open space about 100 yards in front of a collection of approximately 500 low, domed white tents extending up to the foot of the hill behind. The right side of the Land Cruiser was facing the camp, and as we came to a stop, a young man with a clipboard emerged from a makeshift plywood structure that appeared to be serving as some sort of office for the camp and came to greet Pierre. I lowered my window and felt the rain and dampness. My camera bag was open beside me with both cameras still inside. Even before we came to a stop, a small crowd of young men and boys approached the vehicle and—since Pierre was occupied with his conversation at the front window—started to assemble around my window, which at this point was completely open. As with many things in photography, the rest of the story unfolded quite literally in a matter of seconds. Pierre's conversation turned out to be nothing more than the confirmation of a later meeting, which he wanted to do in person because of ongoing difficulties with communications with the camp. It lasted all of 60 seconds.

In the backseat, I was confronted with my very first photographer's dilemma. At my window, just inches away from me, now stood four young men and behind them a small assembly of other young men and boys. Even before I had time to read the tone of the small crowd, I felt the tension. I was a white man sitting comfortably dry in a Land Cruiser, and they were wet and in profound need; their disappointment and resignation to the fact that I had nothing to offer them was immediately palpable. As this instantaneous processing was taking place, I had my moment of realization. I was here to document this. My cameras were at my side. It felt wrong, immediately. But maybe this is what serious photographers have to deal with every day. I turned to my left and grabbed my FM2, which was mounted with a 24 mm wide-angle lens. I turned

back to the window and lifted the camera. A quick framing. A quick focus. And I shot a single frame. I lowered the camera, met the eyes of the young man directly in front of me, felt horrible, and said nothing. Mercifully, from my selfish perspective, Pierre's task was complete and we began to roll out of the camp. I rolled up my window, dried my camera, and sat in silence. My very first experience of sub-Saharan Africa, my first experience of real human beings who had been displaced by conflict, and my first real experience of an ethically fraught photographic transaction, all behind me in less than two minutes.

Back in 1993, there was no preview button on our cameras. I finished shooting that roll of Ektachrome that day and bagged it for processing when we got home, along with the other 59 rolls of film I shot during the rest of the trip. It was more than a month later, when I picked up the slides from Benjamin Film Labs in Toronto, that I first saw the image I had captured. I had a small, cheap, battery-powered slide viewer at home and wouldn't see the image properly projected for another week. But even in the 3x2 inch viewer, the image was stunning. The wide-angle frame covered the full width of the Land Cruiser window, with four faces in the foreground, peering in across the frame. In the background, the mist and heavy sky created atmospheric perspective for the hills in the background, with a few tents visible between the faces. There was a small "office" structure in the mid-background behind the faces to the left, an assortment of faces peering through gaps between the front row of faces, a black umbrella visible at the horizon line, and a hand reaching high in a slightly blurred waving motion between the central faces. The central focus of the photograph is a tall young man, slightly offset to the left of the image, his face framed by the waving hand on the one side and the small office structure on the other. He is wearing a sodden and drooping lemon-yellow loose-knit cotton sweater over a brown T-shirt. His arms are crossed, but only his right hand is visible in the frame across his left arm. A drop of rainwater dangles from his left earlobe like a gleaming miniature pearl earring—an

uncanny point of light that pierces the image.

But what makes the image stunning is this young man's expression. It is no exaggeration to say it has haunted me from the moment I first saw the photograph. His eyes are piercing and angry. He is confronting me. He has seen my like before. He is not disappointed that I am useless in the face of his need—more incredulous and perhaps even disgusted that my instinct in response to this impromptu encounter is to reach for my camera. He is telling me that I have failed to even acknowledge him and his companions as human beings. In the moment, I had decided to treat them as objects for my camera and my readers. Even though I was a master's student in bioethics at the University of Toronto at the time, *he* understood the ethics in this moment far better than I did. I had come, like so many before me, to *take* something from him and his community. I had not brought food, or dry clothes, or an umbrella, or even tea or water. I had come to prosecute my personal agenda, which was remote from his immediate needs, and his expression called me out in a way that was as potent and comprehensive as a Supreme Court decision.

In a speech to the Centers for Disease Control and Prevention staff while he was director in 1984, Dr. Bill Foege said that "if we are to maintain the reputation this institution now enjoys, it will be because in everything we do, behind everything we say, as the basis for every program decision we make, we will be willing to see faces."<sup>21</sup> And in his book *Alterity and Transcendence*, Emmanuel Levinas talks about the ethical significance of encountering the faces of others. He argues that our institutions and politics that are purportedly designed in the pursuit of justice have lost their anchor in obligations to others. He argues that they have succeeded "in making us conceive of the particularity of the human being as negligible and as if it were not that of a uniqueness, but of an anonymous individuality."<sup>22</sup> Elsewhere, in *Totality and Infinity*, Levinas says that "the face opens the primordial discourse whose first word is obligation" and, later, that "the face presents itself, and demands justice."<sup>23</sup> I am indebted to my colleague Dr. Janet Parsons for

introducing me to Levinas's concern with the face. Although I became aware of these ideas many years after I took the photograph described above, they have helped me understand why this photograph has had such a profound effect on me, without a doubt one of the defining experiences that led me to my current career in global health ethics. Levinas's point about the face demanding justice helped me grasp that in the brief moment of that encounter, the expression of the young man who presented his face to me, and captured me squarely in his gaze, reflected the full dark history of failure by people like me to view him as a fully realized human being and to take up his invitation to feel some sort of obligation in light of the extreme peril of his circumstances. Instead of responding in kind by, at the very least, offering my face in a gesture of human acknowledgement, I presented him with my camera. And I literally captured him in a convenient reduction that I could take back to Canada with me and use at my discretion, for my purposes.

I have never published the photograph. And I am all but certain that the young man in my photograph, and all the others who crowded the frame, were killed in the massacre in 1994. In a better world, I would have had the opportunity to share the photograph with him and to offer him my gratitude for the extraordinary education he has given me.

*The necessary photograph: Vignette by Aubrey P. Graham*

I enter the global health scene from the angle of a consultant photographer for humanitarian agencies. After finishing my anthropology dissertation research about the politics of humanitarian photography, I continued to shoot occasional "gigs" for aid agencies and global health organizations across the Democratic Republic of the Congo (DRC). Such consulting opportunities grew from a visual method I employed during my 2013–2014 fieldwork: "direct photography," or photographing for the agencies into the realities of their fieldwork, gaining the ability to see the world through their advocacy-based lenses while encountering their

processes and constraints. These experiences of producing aid photography led me to encounter the ethical decisions involved not just in the selection of images for NGOs' publications but also the decisions central to the daily processes of creating the aid images.

In 2015, the eastern DRC continued to endure the ravages of two international wars—the First Congo War (1996–1997) and Second Congo War (1997–2002)—and the instability they created. North and South Kivu's major cities of Goma, Beni, Butembo, and Bukavu regularly oscillated between periods of conflict and moments of metastable insecurity and back again. Yet the region as a whole was nonetheless plagued by chronic instability—there were more than 50 active rebel groups across North and South Kivu that harassed the population with forced recruitment, the threat and intermittent reality of attack, and the blocking of major arteries for moving goods and people to and from urban economic hubs. Within this context, infrastructural decay, chronically poor health services, disease, and diminished economic opportunities further challenged the region's population and increased the need for and reliance upon humanitarian aid from both international and national NGOs.

In Goma itself—a city I knew well and whose dominant languages (French and Swahili) I spoke—I, as a consultant, could move about independently when photographing for agencies based in the region. At the time, I had my own motorcycle and could ride out to the internally displaced persons camp, the youth centers, the hospitals, or the in-city humanitarian programs and work at my own pace. On the first day of an assignment, this luxury of time allowed me to conduct the required meetings with staff and nod to the official hierarchy, tour the grounds with them, and take no photographs. Then I could return (sometimes frequently) to check in and spend time speaking with the agency participants and beneficiaries to understand the role that the NGO played in their lives. This meant that sometimes I would spend full days with them, often sharing meals, and gaining greater understandings of the depth and complexity of

the situations and individual lives. Such processes led to meaningful relationships, on the one hand, and more creative, evocative photography on the other. Creativity, community, and freedom worked in synergy.

While working in Goma, I often would forget what a luxury that time was until I would accompany agency photographers out of the city on field visits or be shuttled out there under the supervision of the organizations to document their projects. In such cases, once the acronym-encrusted 4x4 would slow to a stop and the red dust cloud that followed it subsided, the NGO team would descend. Spreading out over the project site, the small group typically had less than an hour to get everything accomplished: assess the situation, check in with local management, and create the necessary images to then move to the next site. Assess. Confer. Document. Move on. Repeat.

It was in the process of conducting a slew of photographic success stories in the northern reaches of North Kivu Province with an agency (that I'll call INGOX) that the ethics of the very process of photography came sharply into focus.<sup>24</sup> In 2015, I found myself in the town of Kamango on a short-term consulting contract (together with a Congolese videographer) with INGOX that operated in and around spaces of regional conflict. INGOX aimed to support its local partner NGOs. In this case, I acted as part of its media team, intending to create success stories for the smaller partner organizations that would be hosted on the INGOX website and aimed in part at its donor base.

"In here," said the program lead for a Congolese NGO as he swiftly pushed a maternity ward door open without a knock. "This one [he pointed as he entered], she gave birth last night. Not a complicated birth, but her first one." As sunlight, the program director, and my camera-toting-self filled the door frame, a young woman grasped for a sheet to cover her bare breast and her previously asleep child. The program manager looked back and forth from me to the woman. I remember thinking that I could nearly hear his toes tapping in impatience. It was clear that he needed me to depress the camera's shutter so we could move on—so we could

head over to the next ward, the next clinic, and the next set of photographs. With only a few scheduled hours of media-team time to cover multiple locations, efficiency took precedence over depth. My concern with the young woman's awareness of the goals of the project stood in the way of his opportunity to frame a successful birth and move on. As the on-site program manager, he needed professional images that would transform their underfunded maternal health project into visually compelling stories intended to satisfy international donors and keep the door to further funding open. His lack of explanation and right of brusque entry made it clear that neither the young woman's nor my own comfort with the situation were his primary concern. He simply needed the necessary photographs created in the limited time allotted.

By this time in my photographic career, I had learned to steal time and slow down the process. Swapping between Kiswahili and French, I introduced myself to the young woman, explained who I was, who I was consulting with, and laid out what the potential photographs would be used for, should she consent to having her photograph taken. The program director looked on in irritation. While he never left the small room, she relaxed and explained that she would be happy to contribute her image to the program as they had helped her deliver her firstborn child. As we spoke more about her experience in the clinic—with prenatal care, and about her decision to walk in the day before—I depressed the shutter and worked slowly to capture to her story and craft images celebrating her successful birth within the agency-funded maternity ward. The image that was in the end published by the international umbrella agency framed her laying carefully covered, her left arm acting as a pillow for her head while she beamed diagonally down at her child laying just below the level of her chin on the single-sized mattress. The image aims to show her healthy, happy, and seemingly grateful for the ability to give birth outside of her home in a space staffed by knowledgeable medical staff. That "necessary image" for that site could be checked off the list.

In the process of creating this and similar photographs, I became increasingly aware of the



complex ethical implications of the visual process. At first, the issue of time—or rather, the lack of it—came to the fore. With it arose the issue of respect for and consent of the photographic subject. In comparison to the quantity of time—and therefore care—that I could take on my own schedule in Goma, when in the field with various programs and agencies, time was a valuable commodity. The umbrella or international agencies were responsible for paying per diems, hotel fares, flights, and associated travel expenses for media personnel. The longer these personnel stayed in the field, the more it cost.

As I reflected further on this experience, however, I came to recognize the power dynamics represented in the very bodies of those involved. A grown man in a position of organizational power entered the room in order to provide my camera and body entry. In relation to the gendered dynamics of the eastern Congo and of the NGO itself, the man's presence demanded access and unquestioned consent. The prone new mother was in no literal or figurative position to resist or raise questions. Then I entered. As a foreign female carrying a camera whose images would flow back to Western countries, when my body passed through the doorway of that small maternity room, I did so implicitly embodying a position of extraordinary authority. I held the unexpected power of my race, foreignness, passport, and, perhaps most saliently at the time, the ability to produce authoritative images that would inform donors and INGOX of the potential success of the local maternity program and act as affect-laden documentation in requests for further funding. My presence brought her and her child's body, their representations, and the struggles of the local NGO crashing into a global set of flows, meanings, and expectations.

The quotidian processes and constraints of photography—the assignment topics, the compact schedules, dynamics of gender and privilege, language barriers, involvement of program managers and staff whose jobs relied on positive representations, etc.—pepper an ethical minefield in which power dynamics, consent, and accuracy are often swept out of view in the pursuit of what one could

call the “necessary photograph”—the photograph that justifies, the photograph that has the potential to do the necessary work of documenting, witnessing, and, ultimately, driving funding. In this space, it seems as much the responsibility of the photographer—in this case, me—as well as program managers, field staff, and the media team to slow down in the pursuit of more equitable visual engagement.

### Ethics and global health imagery

Photographing global health images implicates fieldworkers in situations in which differences in power, gender, language, and economics can make it easy for photographers to exploit their subjects and their subjects' circumstances for their personal satisfaction, or for their potential value in the global health visual economy. Situated within that important tension, we argue from hindsight that ethics, while not a perfect or guarantee-able system, must reside more at the forefront of one's mind as one creates the photographic assignment, creates the image, and chooses what to publish. It is the ethics that shapes relationships and can therefore humanize the momentary connections that happen before, during, and after the point at which a camera punctuates an interaction and freezes time and content for later consumption.

Global health ethics, according to Andrew Pinto and Ross Upshur's aptly titled *An Introduction to Global Health Ethics*, is a normative project that includes “both avoiding the enormous risks of doing harm and encouraging individuals to do what is best given a particular set of circumstances and constraints.”<sup>25</sup> Ethical responsibility, in this view, extends beyond the health work itself to the logistical and relational aspects of the programs, including the production and use of photographs to meet the demands of global health's visual economy. As Cook-Deegan's vignette illustrates, by the time a photograph has reached its published form, the ability of the photographer or the organization to avoid doing harm or to encourage what is right with respect to the treatment of the subject(s) is virtually nil. The drive to create images that are

powerful may in fact, as in Lavery's and Graham's respective vignettes, lead to an ethical trade-off between the opportunity cost to the photographer and organization of not taking the photograph at all and the potential value of the image within the global health visual economy.

This is not to say that there have not been positive strides in the field of human rights and global health images in recent decades. Out of the rank suffering of the Global South photographed and published in the 1980s and 1990s came ethical codes of conduct surrounding the publication of image content, as well as individualized photo and media policies for global health agencies.<sup>26</sup> The Code of Conduct on Images and Messages—drawn up by the European NGO Confederation for Relief and Development (CONCORD)—has made important strides in reducing harmful image content and promoting dignified photographs of agency participants and beneficiaries. They note that “accordingly, in all our communications and where practical and reasonable within the need to reflect reality, we strive to: Choose images and related messages based on values of respect equality, solidarity and justice ... Avoid images and messages that potentially stereotype, sensationalize or discriminate against people, situations or places.”<sup>27</sup> And while these guidelines are essential in promoting equitable and ethical depictions of situations, by the time these photographs are seen by other people—by the time they are ready to be “chosen”—it's already too late for real ethical engagement. Rather, we're advocating for a switch in the ethics to emphasize the ethical importance of the *process* of the production of photographs, not solely more judiciousness in the use of photographs that have already been taken.

## Conclusion

Ethics has a place in assessing the representational content of the image. But it ought to remain in the forefront throughout the entire photographic process—informing, in particular, which images to take, how to take them, and where those images later travel. While our retellings and analysis recognize the importance of what is signified in the image,

we expand beyond addressing image content alone to bring our experiences as photographers into the scope of ethical concerns. We recognize the challenge of capturing a compelling photograph in the space of complex international relations and dire local conditions. We show how the reflex to photograph can, in ways, preclude the humanness of an encounter, shielding the photographer from the subject and creating a response that, while compelling, lacks the striving for equity that lies at the center of global health. Further, our photographs—and emotional reactions they produce—speak to both the very need for the image and the desire for it to capture what will literally “work” for the agencies that commission their production.

In showing that ethics starts long before the choice to publish a photograph, we engage global health photography as a relationship. Moreover, it is a relationship built of unequal power dynamics, where agency is held (albeit lopsidedly) by all of those around the camera—the subject, the photographer, and the bystanders or actors who exist beyond the photograph's composition. By following the concept of “encouraging people to do what is best given certain circumstances and constraints,” we as photographers and global health workers call for action to craft slower, more intentional, better informed, human, humane relationships across the body of the camera.<sup>28</sup>

Drawing from our vignettes, such hindsight compels us to think about how to improve in the future. How can we channel these experiences to help educate younger generations of global health field workers and photographers about the ethical implications that are inherent in the process of photography? Doing so requires an understanding that each image arises from a set of momentary, fragmented relationships embedded in asymmetrical power relations and that the act of clicking the shutter bonds the photographer to the circumstances and ethics of the image's production and begins the ethical journey of determining its appropriate use. Perhaps a desired outcome could be that rather than responding with the photograph as a reflex, or asking, “Is this a good global health photograph?” or “Will this image work for X agency?,” we might

also ask, “Is this an ethical engagement that will equally produce an ethical image?” In so doing on an international scale, it is possible to imagine that we as global health workers and image producers could shift the genre’s visual priorities and reshape not only the visual economy of global health images but ultimately the very act of photography in the field. Perhaps, then, photography-based interactions could go beyond securing the “necessary photograph” aimed at witnessing, documenting, and advertising, to rather crafting photographs that are, at each encounter in their process, shaped by care and focused on a more equitable, human interaction across the lens.

## References

1. A. Pinto and R. Upshur, “Introduction,” in A. Pinto and R. Upshur (eds), *An introduction to global health ethics* (Abingdon: Routledge, 2013).
2. L. Chouliaraki, “Post-humanitarianism: Humanitarian communication beyond a politics of pity,” *International Journal of Cultural Studies* 13/2 (2010), pp. 107–126; H. Fehrenbach and D. Rodongo (eds), *Humanitarian photography* (Cambridge: Cambridge University Press, 2015); A. Graham, “Take this picture”: *Humanitarianism and the politics of photography in the eastern Democratic Republic of the Congo*, dissertation, Emory University (2016).
3. M. Givoni, “Beyond the Humanitarian/political divide: Witnessing and the making of humanitarian ethics,” *Journal of Human Rights* 10/1 (2011), pp. 55–75; M. Givoni, “Humanitarian governance and ethical cultivation: Médecins sans Frontières and the advent of the expert-witness,” *Millennium-Journal of International Studies* 40/1 (2011), pp. 43–63; Fehrenbach and Rodongo (see note 2); Graham (2016, see note 2).
4. D. Poole, *Vision, race, and modernity: A visual economy of the Andean image world* (Princeton: Princeton University Press, 1997), p. 8.
5. Ibid. pp. 8, 12.
6. Ibid.
7. A. Kleinman and J. Kleinman, “The appeal of experience; the dismay of images: Cultural appropriations of suffering in our times,” *Daedalus* 125/1 (1996), pp. 1–23; S. Moeller, *Compassion fatigue: How the media sell disease, famine, war and death* (London: Routledge, 1999); S. Sontag, *Regarding the pain of others* (Paris: Diogenes, 2003); D. Campbell, “The iconography of famine,” in G. Batchen, M. Gidley, N. K. Miller, and J. Prosser (eds), *Picturing atrocity: Photography in crisis* (London: Reaktion, 2012), pp. 79–92; G. Batchen, M. Gidley, N. K. Miller, and J. Prosser, *Picturing atrocity: Photography in crisis* (London: Reaktion, 2012).
8. Sontag (see note 7), p. 78.
9. Kleinman and Kleinman (see note 7), p. 19.
10. J. V. Lavery, P. O. Tinadana, T. W. Scott, et al., “Towards a framework for community engagement in global health research,” *Trends in Parasitology* 26/6 (2010), pp. 279–283.
11. L. Haber, *The poisonous cloud: Chemical warfare in the First World War* (New York: Clarendon Press, 1986).
12. P. Dunn, “The chemical war: Journey to Iran,” *NBC Defense and Technology International Journal* (April 1986), pp. 28–37; Physicians for Human Rights, *Winds of death: Iraq’s use of poison gas against its Kurdish population* (Cambridge, MA: Physicians for Human Rights, 1989), pp. 37–38.
13. J. Ali, “Chemical weapons and the Iran-Iraq War: A case study in noncompliance,” *Nonproliferation Review* 8/1 (2001), pp. 43–58.
14. Government of Canada, *Handbook for the investigation of allegations of the use of chemical or biological weapons* (Ottawa: Government of Canada, 1985).
15. Physicians for Human Rights (see note 12); H. Hu, R. Cook-Deegan, and A. Shukri, “The use of chemical weapons: Conducting an investigation using survey epidemiology,” *JAMA: Journal of the American Medical Association* 262/5 (1989), pp. 640–643.
16. 101st Congress: S. 8, S. 195, S. 238; H.R. 696, H.R. 3033, H.R. 4585, H.R. 4653, and H.R. 5431.
17. R. H. Sandler, P. R. Epstein, R. M. Cook-Deegan, and A. Shukri, “Initial medical assessment of Kurdish refugees in the Turkey-Iraq border region,” *JAMA: Journal of the American Medical Association* 266/5 (1991), pp. 638–640.
18. G. Roberts, “Winds of death,” in G. Roberts (dir), *Dispatches*, UK Channel 4 television (1988).
19. Amnesty International, “In Turkish prisons: A report from Amnesty International,” *New York Review of Books* (1985).
20. S. McCurry, photograph of Sharbat Gula accompanying “Along Afghanistan’s War-Torn Frontier,” by Debra Denker, *National Geographic Magazine* 167 (June 1985) and accompanying C. Newman, “A Life Revealed,” *National Geographic* 201 (April 4, 2002).
21. D. Addiss, “Global elimination of lymphatic filariasis: A ‘mass uprising of compassion,’” *PLoS Neglected Tropical Diseases* 7/8 (2013).
22. E. Levinas, *Alterity and transcendence* (New York: Columbia University Press, 1999), p. 176.
23. E. Levinas, *Totality and Infinity* (New York: Springer Publishing, 1991), pp. 207, 294.
24. For further detail on this particular aid mission and the issues of conflict and image making, see A. Graham, “Covering emergency: NGO photographs of stability in a space of ongoing conflict,” in C. Ndaliko and S. Anderson (eds), *Art of emergency: Aesthetics and aid in African crises* (Oxford: University Press, forthcoming).

25. Pinto and Upshur (see note 1), p. 11.

26. L. Malkki, "Speechless emissaries: Refugees, humanitarianism, and dehistoricization," *Cultural Anthropology* 11/3 (1996), pp. 377-404; K. Manzo, "Imaging humanitarianism: NGO identity and the iconography of childhood," *Antipode* 40/4 (2018), pp. 632-657; Batchen et al. (see note 7).

27. CONCORD, *Code of conduct on images and messages* (2012). Available at <https://concordeurope.org/wp-content/uploads/2012/09/DEEEP-BOOK-2014-113.pdf>.

28. Pinto and Upshur (see note 1), p. 11.

# Results Communication in Breast Milk Biomonitoring Studies: A Scoping Review and Stakeholder Consultation

ALYSSA MARI THURSTON, FEDERICO ANDRADE-RIVAS, AND JERRY M. SPIEGEL

## Abstract

Researchers investigating breast milk contamination face substantive ethical dilemmas regarding how biomonitoring results should be conveyed, with limited guidance available to help them. To identify effective processes for undertaking such research, we sought to critically assess practices being followed in reporting results. To consider how researchers have reported on this and related ethical issues, we searched three English-language databases for articles published between 2010–2016 on measuring presence of pesticides in breast milk. Data on report-back processes and discussed ethical issues were charted from retained articles (n=102). To deepen our understanding of issues, we further consulted authors (n=20) of retained articles through an online survey. Quantitative data from surveys were tabulated and qualitative data were analyzed thematically. Of 102 articles, only two mentioned sharing results with subjects, while 10 out of 20 survey participants confirmed that they had indeed conducted report-back in their studies. Articles discussing ethical considerations were few (n=5), although researchers demonstrated awareness of common ethical debates to inform report-back decisions. Our review suggests that greater explicit attention should be given to practices of engaging study subjects and their communities in contamination studies so that an evidence base on best ethical practices can be more readily available.

---

ALYSSA MARI THURSTON is an MSc public health student at the London School of Hygiene and Tropical Medicine, London, UK.

FEDERICO ANDRADE-RIVAS, MPH, is a PhD student at the Global Health Research Program, School of Population and Public Health, University of British Columbia, Canada.

JERRY M. SPIEGEL, MA, MSc, PhD, is co-director of the Global Health Research Program at the School of Population and Public Health and professor, University of British Columbia, Canada.

Please address correspondence to Jerry M. Spiegel. Email: [jspiegel@mail.ubc.ca](mailto:jspiegel@mail.ubc.ca).

Competing interests: None declared.

Copyright © 2019 Thurston, Andrade-Rivas, and Spiegel. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted noncommercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

## Introduction

Pollution, including chemical pollution, not only undermines the fundamental right to a safe and healthy environment, but has been identified by global disease burden assessments as one of the greatest threats to human health.<sup>1</sup> Responding to this, human biomonitoring (HBM) is increasingly pursued as a way to assess chemical exposure and provide additional evidence to that obtained through environmental monitoring of soil, water, and food.<sup>2</sup> Analysis of biomarkers of exposure in samples of blood, urine, hair, nails, breast milk, and saliva directly assess the body burden of hundreds of chemicals and their metabolites.<sup>3</sup> While HBM provides a way to assess chemical exposure at individual and population levels, an emergent issue within the field of toxicology and environmental health is the ethical challenge of results disclosure and communication with research subjects in studies using HBM as a tool for environmental health risk assessment. The last decades have seen a rise in debates among groups of concerned scientists, ethicists, activists, and other stakeholders on how appropriate it is to communicate biomonitoring results to research subjects, what information should be communicated, and how communication should be conducted.<sup>4</sup>

In recognition of these challenges, we sought to draw on identified best ethical practices to inform the conduct of our research responding to an Ecuadorian community's concerns about the impact of intensive pesticide use, as part of an ongoing international research program investigating associations between food systems and health equity. The ethical issues were of particular importance to us as our research applies the Latin American Social Medicine orientation to health equity, which considers those affected as not only participants in the research process but also as active agents (recognized as *subjects* in the language of this approach) in the process of pursuing their right to health.<sup>5</sup> This is in a manner consistent with the participatory action research orientation to community engagement in "Western" health research approaches that has challenged the more passive framing of "research subjects" as essentially

an entity for researchers to observe.<sup>6</sup>

With our study approach including measurement of pesticide concentrations in breast milk, we were especially apprehensive that reporting results in conformity with the right to know about the health threat posed by exposure to toxins could cause undue fear among mothers and discourage breastfeeding, which itself has been recognized as a human right of the mother/child dyad.<sup>7</sup> We quickly observed that despite the growing body of literature highlighting issues involved and the benefits of potential approaches, no assessment of results communication practice, strategies, and considerations had, to our knowledge, been conducted to inform this research. To address this knowledge gap, we initiated this sub-study to critically assess how results communication in breast milk contamination studies are conducted and reported.

## Conceptualizing the challenges

To situate our study objectives within existing discussions on the issue, here we aim to synthesize key debates, broadly categorized into 1) whether or not to communicate biomonitoring results to research subjects; and 2) if communication is deemed appropriate, who should communicate results with subjects, what should be communicated, and how should it occur.

### *To communicate or not*

Decisions to conduct report-back are influenced by a variety of ethical considerations, including scientific uncertainties associated with biomonitoring data and their insights into potential health effects—as well as what can be done with this information. While HBM is undoubtedly useful to provide evidence that exposure and uptake of a pollutant in question has taken place, results can only provide a snapshot of an individual's exposure to a particular chemical and cannot reflect exposure throughout one's lifetime, the interaction of the chemical with other body burdens, or potential sources of the exposure.<sup>8</sup> Furthermore, the considerable lag in scientists' ability to understand individual health implications of exposures in comparison to the



rapid advancement in technology to detect pollutants challenges scientists to find meaning in single-measurement data and ways to appropriately advise subjects on personal exposures.<sup>9</sup> Uncertainties with the value and implication of HBM data lead some to argue that report-back should only occur if results have known association to an adverse health outcome to avoid causing unwarranted fear and anxiety over results that may have no clinical relevance.<sup>10</sup> Some researchers measuring exposure of pollutants with established clinical levels (for example, lead or mercury) have conducted timely report-back to subjects whose results exceed acceptable levels.<sup>11</sup>

The concern of causing undue fear is underscored in sensitive cases like biomonitoring of breast milk, as some emphasize that anxiety over individual-level results may cause mothers to reduce or stop breastfeeding altogether.<sup>12</sup> The widespread consensus that breast milk is the most appropriate form of nutrition for infants thus makes the risk of HBM results influencing mothers' decisions regarding breastfeeding a particularly difficult ethical challenge. However, evidence on actual behavioral and psychological impacts of body burden knowledge on subjects remains inconclusive. Findings from a limited number of studies on this issue are mixed, where some have found that subjects experience some degree of anxiety, frustration, or guilt over their results, while others found subjects are not excessively worried about their individual results or can even feel empowered to take action to reduce their exposures.<sup>13</sup> A survey by Geraghty et al. based on hypothetical scenarios suggested that concerns over breast milk contamination may cause mothers to terminate breastfeeding prematurely, while Wu et al. found that mothers who received individual breast milk biomonitoring results in their study did not change their breastfeeding behavior.<sup>14</sup>

Another source of debate stems from ethical considerations of HBM report-back for marginalized, disadvantaged, and vulnerable communities or cultural groups that may be at heightened risk of exposure to harmful toxicants based on historical and existing environmental injustices.<sup>15</sup> Some express concerns on communication of results in

this context as potentially further marginalizing vulnerable subjects or undermining the gravity of underlying political, historical, and social issues by employing a primarily individualized risk assessment lens to environmental health problems that manifest at a broader scale.<sup>16</sup> In communicating results to socioeconomically disadvantaged subjects, researchers express concern that knowledge of body burdens among subjects with limited capacity and means to reduce exposures would only cause feelings of frustration and powerlessness.<sup>17</sup> On the other hand, Adams et al. found that through open communication and involvement of trusted community organizations, researchers are able to inform subjects from disadvantaged backgrounds in ways that promote actions to mitigate exposures.<sup>18</sup> Others view disclosing individual results as an important way to rectify historical abuses, exploitations, and neglect of individuals and communities involved in research by diminishing disparities in information access and autonomy, as well as by promoting transparency and building trust between researchers and subjects.<sup>19</sup> The potential for scientific evidence on body burdens to demonstrate the injustices suffered by marginalized groups is also rationalized as a reason to communicate results to subjects, communities, and policy-makers, given its potential to spur action for environmental management.<sup>20</sup>

Alongside these debates, guidance and decisions on disclosure of HBM results are also varied among Institutional Review Boards (IRBs) that oversee the ethical pursuit of research. Some IRBs have denied researchers' requests to communicate results with subjects due to similar concerns of causing undue fear among subjects and uncertainty in the value and meaning of biomonitoring data, while some have supported report-back if these scientific uncertainties were clearly explained to subjects.<sup>21</sup> In other instances, IRBs have fully supported report-back of results or were inconsistent in their decisions.<sup>22</sup> Variation in IRBs decisions and rationale to approve or reject report-back highlights the lack of consensus on appropriate practices. A study by Ohayon et al. suggested that IRB members with limited experience with HBM were more con-

cerned with scientific uncertainties and potential harms of results communication, whereas those with more experience viewed report-back favorably and as the moral course of action.<sup>23</sup>

Within the multitude of debates that question the ethics and suitability of results disclosure, proponents of report-back firmly point to researchers' moral obligation to communicate results, subjects' right to know their personal body burdens, and the benefits of subjects knowing their individual results.<sup>24</sup> These benefits include improving environmental health literacy among subjects, encouraging individual and collective action to mitigate exposures, as well as enriching research itself by improving study participation and generating new perspectives.<sup>25</sup> Furthermore, Quigley argues that denying subjects decision-making information to reduce exposures would be unjust if it turns out that worry was not undue and detected levels may indeed cause adverse health effects.<sup>26</sup> Importantly, a growing number of studies indicate that subjects themselves overwhelmingly want to know their individual results.<sup>27</sup> Despite some researchers' desire to communicate HBM results to subjects, there is a general lack of guidance on appropriate report-back strategies and in particular, on sensitive cases like biomonitoring of breast milk or involvement of subjects from marginalized or disadvantaged backgrounds.<sup>28</sup>

### *Results communication strategies: who, what, and how*

If report-back is deemed appropriate on the basis of these ethical considerations, researchers are faced with more debates and difficult decisions regarding communication strategies. In terms of who should communicate results to subjects, some argue scientists are best positioned for report-back, as they possess knowledge on the uncertainties surrounding their research and ability to ensure that no misinterpretation of the data occurs.<sup>29</sup> Others suggest communication should occur by researchers in conjunction with, or entirely by, health professionals who are able to relay the clinical significance of subjects' individual results, while some researchers express concern that clinicians may be limited in

their ability to advise on individual results without specific knowledge and training on environmental health.<sup>30</sup> For breast milk biomonitoring, involving lactation specialists or NGO workers with experience in breastfeeding promotion as part of the report-back strategy has been noted as good practice.<sup>31</sup> Studies have also recommended involving counselors and local community representatives in the report-back process, as well as a contact person that subjects can refer to for inquiries on their results throughout the duration of the study.<sup>32</sup> In cases where researchers are sharing control of the study through participatory research strategies, it may be considered that local collaborators lead communication and establish an approach to report-back adapted to community needs and context.<sup>33</sup>

In terms of what to communicate, several guidance documents call for report-back of individual-level results.<sup>34</sup> Some researchers recommend reporting individual results along with the study aggregate results, or results from comparable studies, in order to contextualize and promote understanding of personal levels of contamination.<sup>35</sup> Where individual implications of exposures and specific health outcomes are unknown, some suggest report-back of aggregate study results instead of individual results.<sup>36</sup> Moreover, aggregate results may also be most appropriate in cases where individualized results may cause discrimination of individuals (for example, in obtaining employment or insurance).<sup>37</sup> Beyond the type of results to be included for report-back, researchers suggest including explanations on what is known on health implications and exposure mitigation as part of what is communicated to subjects.<sup>38</sup>

In addition, researchers have offered suggestions with regard to strategies on how to communicate biomonitoring results to subjects. Some researchers have reported results through reports and workshops or meetings, while the World Health Organization (WHO) has created an information sheet for dissemination to mothers involved in breast milk biomonitoring studies.<sup>39</sup> Researchers emphasize the importance of offering results in a variety of ways, including text, graphs, diagrams, or pictures, to be mindful of different literacy

levels and communication preferences.<sup>40</sup> In terms of mode of report-back, results have been communicated in person to give subjects an opportunity to ask questions, while a review of participants' preference found that results shared via mail were deemed satisfactory, but some preferred face-to-face contact in general or in cases of negative results.<sup>41</sup> Both passive and active forms of report-back have been practiced, in which subjects could contact the research team if they wanted to receive their individual results or where the researcher actively offered subjects their results.

## Methods

Acknowledging the lack of consensus regarding reporting back HBM results, and the particular ethical concerns of human breast milk pesticide contamination studies, we designed a methodology to assess how results communication is being discussed and conducted in this type of research.

### *Review of literature*

To thoroughly map how results communication is being conducted and reported in breast milk contamination studies, we conducted a scoping review guided by the Arksey and O'Malley approach for scoping studies, as revised by Levac et al.<sup>43</sup> We searched three prominent databases (PubMed, Medline, and Toxline) for peer-reviewed articles related to pesticide contamination of breast milk, using the keywords "pesticide"; "breast milk" or "human milk"; and "contamination." The scope of the search was limited to articles published between January 2010 and October 2016, when our team started the review process. We excluded articles that were 1) not published in English; 2) un-

related to the topic or did not analyze human breast milk as part of the study methodology; 3) focused on the methodology of analyzing breast milk and not on exposure to a pollutant; and 4) reviews. Two reviewers were engaged in the review of articles for inclusion, with a third global health practitioner with expertise in environmental health adjudicating discrepancies.

Selected articles were then examined to assess whether or not they mentioned having conducted report-back to research subjects. If studies reported communicating results, we charted the chosen method of report-back (for example, a brochure or workshop) and the type of data that was reported, including individual-level, aggregate-level, or pooled results (that is, samples from study population mixed for analysis). Articles with any discussions on ethical considerations of report-back relating to breast milk contamination were also noted. As well, we recorded if articles investigated 'exposure' or 'effect', where the purpose of 'exposure' studies was to document exposure levels of some pollutant in breast milk and the purpose of 'effect' studies was to investigate the presence of some suspected health effect. Two reviewers independently extracted and charted data in terms of designated categories (Table 1).

### *Survey of researchers*

Research teams who produced the articles included in our review were then contacted in order to obtain further insights with regards to ethical discussion and results communication beyond the information available in the assessed publications. Teams were requested to participate in a survey of ten quantitative and qualitative questions (see Appendix 1). Contact persons for each article were identified and

TABLE 1. Categories of results communication approaches reported in articles

1	Results communication to research subjects not mentioned
2	Pooled results communicated to research subjects
3	Aggregate-level results communicated to research subjects
4	Individual-level results communicated to research subjects
5	Ethical discussions on communicating biomonitoring results

duplicates of individuals who served as contacts for more than one retained study were removed. Email invitations to participate in the survey included preliminary findings from the review to engage participants with the critical issues identified and provide opportunities to address knowledge gaps. Survey results were collected anonymously to ensure participants were able to voice their opinions freely on the sensitive topic. Ethical approval was granted by the University of British Columbia's Behavioural Research Ethics Board.

Results for closed-ended questions were tabulated, while results for open-ended questions were organized and analyzed by emergent themes. Two researchers conducted this process independently, and themes obtained were later discussed and reflected upon to produce a unified analysis.

## Results

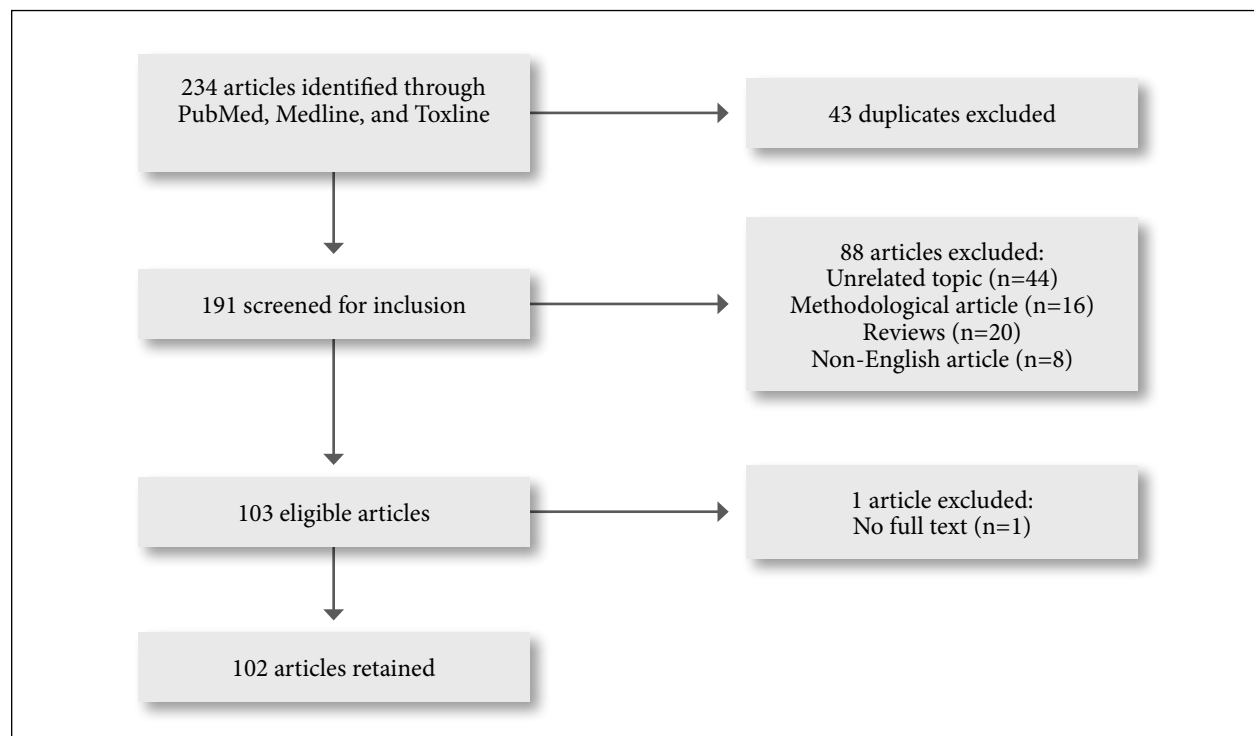
### *Study selection and characteristics*

After removal of 43 duplicates, 191 articles were screened for inclusion based on our eligibility criteria.

All articles retained were published in English and measured some level of exposure to a pollutant via breast milk biomonitoring. Articles on unrelated topics (n=44), articles focused on methodology of how to conduct breast milk biomonitoring (n=16), review articles (n=20), non-English (n=8), and articles without full text (n=1) were excluded from our search. This inclusion/exclusion strategy resulted in the retention of 102 articles from 234 articles that were identified (Figure 1).

Of the 102 retained articles that measured exposure to some pollutant through breast milk biomonitoring, 14 articles also investigated some suspected health effect. While "pesticide" was used as a search term to focus the review on our interest in breast milk contamination of pesticides, we retained any article returned in the search that measured other pollutants, as similar ethical issues on report-back would prevail regardless of the type of pollutant. We made note of studies investigating exposure to mercury and lead, as pollutants with established guidance values may have impact on researchers' decisions to communicate results with

FIGURE 1. PRISMA flow diagram for article selection



Source: Diagram produced based on guidelines by Moher et al.<sup>44</sup>

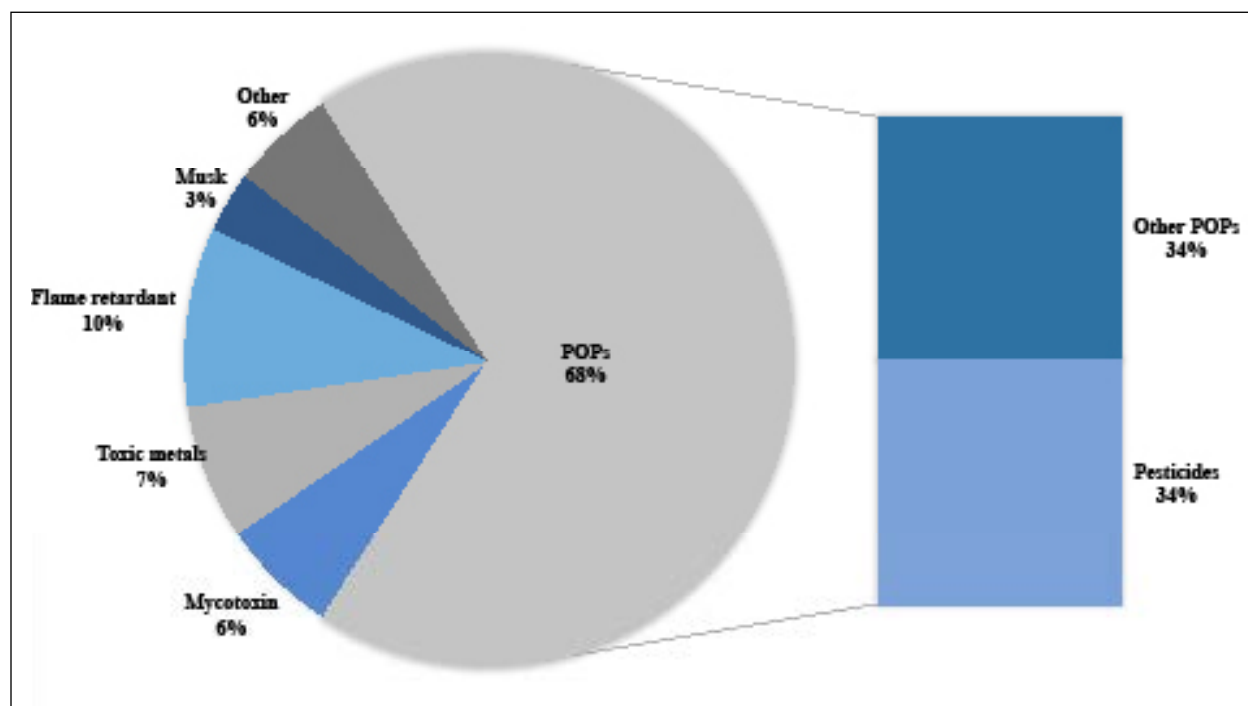
their subjects.<sup>45</sup> Among all pollutants reflected in retained articles, Persistent Organic Pollutants (POPs) consisted 68%, with half of this number (34%) specific to pesticides. Musk, flame retardants, toxic metals, mycotoxins, and other pollutants (for example, bacteria, radioactive pollutants, and mineral oils) were also reflected in articles (Figure 2).

### Review of literature

First, our team sought to determine how many articles reported communicating results to participants within their publications. Based on the review of articles, 100 out of 102 articles did not indicate any report-back of results to research subjects. Of the two articles that indicated communication of results to subjects, Rojas-Squella et al. reported individual and aggregate-level results through a breastfeeding workshop and in subjects' homes, while Wasser et al. reported pooled results to subjects (see Table 2).<sup>46</sup> Rojas-Squella et al. explained that finding uniform guidance on appropriate report-back methodology was a challenge, necessitating consultation with other researchers who had

conducted similar studies in developing countries.<sup>47</sup> Their decision to communicate both individual and aggregate-level results was based on recommendations from other researchers, as it was suggested that aggregate results contextualize and promote better understanding of individual results.<sup>48</sup> Of the 12 articles that were labeled as 'effect' studies and the 11 articles investigating exposure to mercury and/or lead, none discussed conducting report-back. Table 2 summarizes the report-back strategies and ethical considerations reported in the articles included in this study.<sup>49</sup> Only five of the reviewed articles included some discussions on ethical considerations relating to report-back of breast milk biomonitoring results. These primarily focused on how findings of studies should not discourage breastfeeding. Rojas-Squella et al. explained that while the adverse health effects of their pollutant of interest are not entirely known, the benefits of breastfeeding likely outweigh potential harms.<sup>50</sup> Others highlighted the importance of report-back and providing information to subjects, and stated that findings should be used to inform subjects' choices to mitigate exposure and overall efforts for

FIGURE 2. Pollutants reflected in retained articles





environmental management.<sup>51</sup>

### Survey of research teams

After removal of duplicate contact persons and invalid contact information, we contacted 82 research teams from retained articles and 20 participated in our survey (24.4% response rate). From quantitative survey questions, we found that 10 out of 20 researchers had conducted report-back in their studies, while the other 10 had not. It is worth noting that survey responses were collected anonymously, thus it is possible that the authors of the two articles identified to have conducted report-back through the literature review were also among the 10 identified in the survey. Researchers had communicated individual-level, aggregate-level, and pooled results to subjects through breastfeeding workshops, dis-

tribution of reports, and general media (see Figure 3). One respondent elaborated that their workshop included health care workers who were experts in the field of environmental exposure and breastfeeding promotion. Another indicated that while their team had distributed reports to subjects, they would have ideally included a workshop despite being difficult to organize. Researchers believed that health care workers, research teams, and municipal/community workers had similarly important roles in report-back processes (see Figure 3).

Researchers had mixed perspectives on the usefulness of academic journals in environmental health as platforms to discuss ethical considerations regarding report-back (see Figure 3). One researcher who agreed with pursuing this avenue elaborated that their team had previously used

TABLE 2. Overview of report-back strategies and ethical considerations reflected in articles

Author(s) (year)	Sample size	Study aims	Report-back strategy	Ethical considerations/discussion
Wasser et al. (2015)	Sample size=52	To assess the concentrations of Persistent Organic Pollutants (POPs) in pooled breast milk sample of women from three medical centers in Israel	Type of results= Pooled  Method= Not discussed	Not discussed
Rojas-Squella et al. (2013)	Sample size=32	To assess the presence of Organochlorine Pesticides (OCPs) in breast milk in a sample of women in Bogota, Colombia	Type of results= Individual and aggregate-level  Method= Report-back in a breastfeeding workshop or in subjects' homes	Selection of report-back strategy, issues with lack of uniform guidance on report-back, the importance of report-back, and how the benefits of breastfeeding outweigh potential harm
Gebremichael et al. (2013)	Sample size=101	To determine the levels of OCP residues in human and cow milk samples from three towns in Southwestern Ethiopia	Not discussed	Ensuring breastfeeding is not discouraged based on the findings; provision of information and education of public to reduce exposure levels
Guerranti et al. (2013)	Sample size=49	A pilot study to assess distribution and levels of PFOS and PFOA in breast milk of women in Tuscany, Italy	Not discussed	Findings should not discourage breastfeeding but be used by doctors to recommend healthy lifestyles and food choices to pregnant women
Behrooz et al. (2011)	Sample size=80	To assess mercury concentration in breast milk and the health risks of mercury exposure in infants in Iran	Not discussed	The need to provide mothers with information on contaminants and benefits of breast milk
Darnerud et al. (2011)	Sample size=28	To assess the presence and levels of brominated flame retardants and chloro-organic compounds in breast milk of population in Limpopo province, South Africa	Not discussed	Findings should not discourage breastfeeding but be used to inform efforts to mitigate environmental contamination

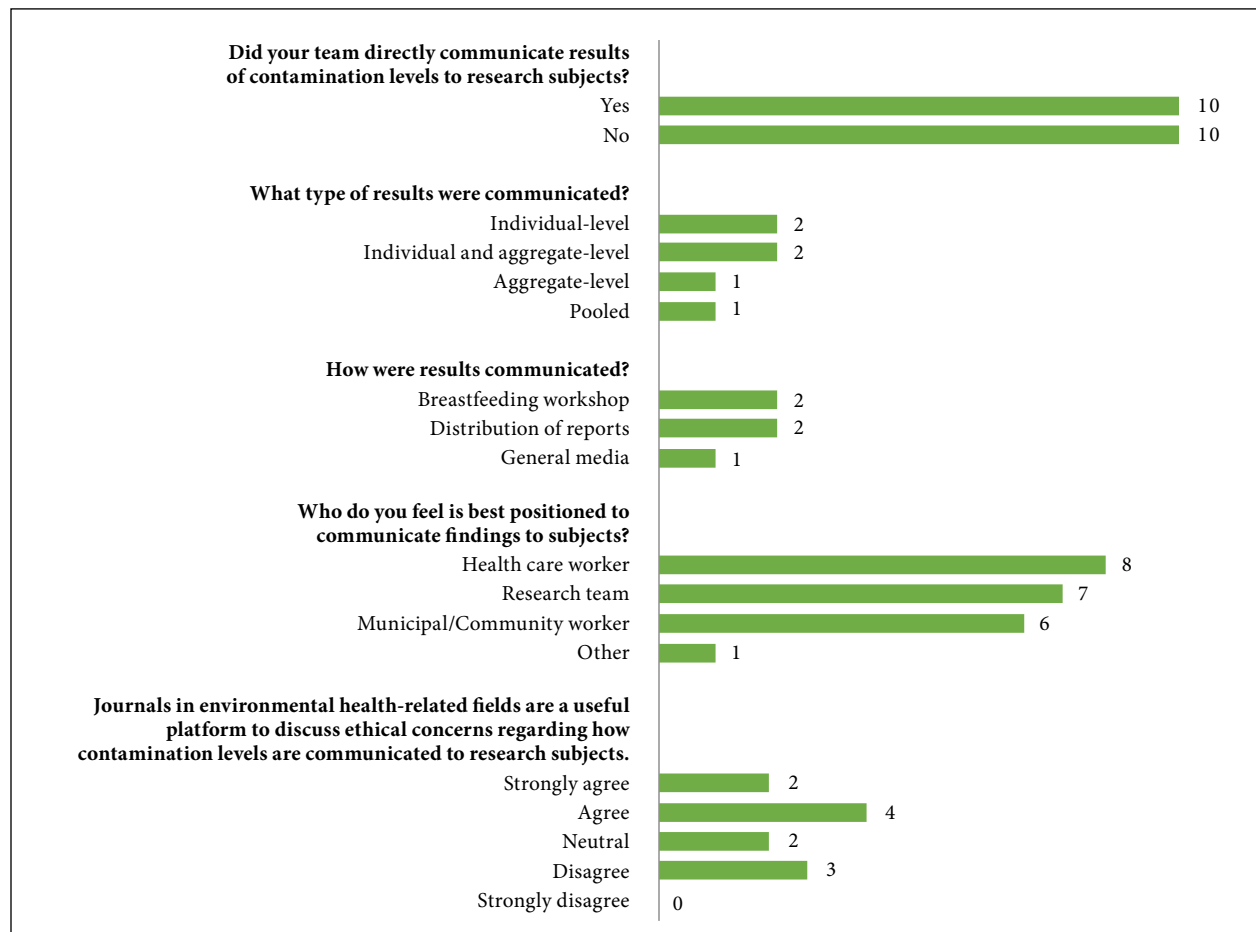
academic journals in this field to discuss experiences with report-back (but had not done so for the study included in this review, as they had used anonymized samples from biobanks).

From qualitative questions, three broad themes emerged on considerations behind report-back and related challenges. The first theme covered various perspectives and reasons for conducting report-back. Respondents discussed communicating results with subjects to ensure that they were provided the right message and that study findings did not discourage breastfeeding. Three respondents mentioned that report-back should be conducted to inform subjects on their exposures and the topic in general, while one added that report-back was a form of compensation to subjects for participating in their study. Others specified that report-back was only conducted in cases where results appeared

to be of clinical significance or were only permitted to do so by IRBs (see Box 1).

The second theme that emerged focused on researchers' rationales for *not* conducting report-back. Concern that communication of results might discourage breastfeeding was prominent in this regard. Additional attention was drawn to communities' level of understanding, scientific uncertainty, and inability to mitigate exposure. One researcher further explained that they decided against report-back because the community's level of understanding on the topic may have caused more harm in the context of their study. Explicit denial of report-back specified by IRBs was reported by two researchers, with one attributing this to concerns of causing undue fear, as well as issues with scientific uncertainty and subjects' inability to mitigate exposures. Other reasons that were raised

FIGURE 3. Results from quantitative survey questions



Note: Results in green reflect researchers' report-back practices and results in blue are relevant opinions.

included report-back not being the objective of the study, and lack of contact with subjects due to logistical issues or use of biobank samples. However, some researchers who lacked contact with subjects explained that they believe report-back is important and must be done without causing anxiety among mothers (see Box 2).

The last emergent theme was on challenges that researchers identified regarding processes of reporting back on findings. A common issue was lack of guidance within publications and from IRBs, where one respondent explained having to contact other researchers directly as a result of difficulties with finding advice on report-back within publications. Navigating the duty to share results

with subjects while ensuring results do not cause undue fear, as well as limitations of scientists' understanding of health implications and mitigation of exposures, were raised as challenges to conducting appropriate report-back. One respondent discussed the risk of miscommunication due to researchers' lack of training in risk communication as a challenge (see Box 3).

## Discussion

While studies examining selected researchers' perspectives on report-back through interviews or focus groups have suggested a level of awareness of ethical issues among scientists, this orientation was

### Box 1. Reasons for report-back

**Concern of discouraging breastfeeding**

"We were concerned that this study...could send the wrong message that breast-feeding should not be done because of the toxics in breast-milk. We wanted to make sure that this was not the message."

"We did not want to disincentivize breastfeeding, and we wanted to make sure that women could understand in context the results of the study."

**To inform subjects on exposures**

"In my opinion, communicating the results to research subjects will be better in order to inform them about their contamination levels. We only published the results."

"[Results communication] is an essential part of such research. The public should be aware of environmental concerns."

"We understood that this is a sensitive topic and wanted our participants to be informed as compensation for their contribution."

**Results were of clinical significance**

"The results were not used for clinical decision making unless the clinical team felt strongly that the results were required to ensure patient safety."

"The Ethical Committee did not authorize us to directly inform participants. If a mother had milk with a too high level of [exposure], the doctor had informed her."

### Box 2. Reasons against report-back

**Concern of discouraging breastfeeding**

"Level of understanding of the community about the subject and possibility of mothers discontinuing breastfeeding... might have caused more anguish and infections of babies."

**Denial from IRBs**

"Ethical committee considered it premature to inform on individual levels as individuals cannot protect themselves from environmental contamination, scientific evidence for individual risk assessment not strong enough and thus creation of undue concerns/worries plus risk of feeling guilty in pregnant women."

**Not the objective of research**

"We chose to not communicate the results since they were screening results, purely for the research purpose."

**Lack of contact with subjects**

"It was difficult to find the participants to report the results."

not widely reflected in our study of contaminant studies published between January 2010 and October 2016.<sup>52</sup> With only 2 out of 102 articles reviewed for this study explicitly presenting experiences in report-back of results to subjects, it is apparent that the vast majority of research teams either did not communicate results with subjects, chose not to discuss strategies and considerations for report-back within their articles, or potentially chose to discuss this in other publications or platforms. Articles that included at least some discussion of the sensitive nature of report-back, the importance of encouraging breastfeeding despite findings of contamination, the need to communicate findings with subjects, or other relevant ethical topics were similarly few (5 out of 102).

We initially hypothesized that scientists conducting biomonitoring research may be motivated to share experiences and best practices for report-back within publications, partly in recognition of the lack of formal guidance and emergence of debates on related ethical issues over the years, as documented by LaKind et al. in their 2008 article on polybrominated diphenyl ethers in breast milk in the United States.<sup>53</sup> To better understand research practices in reporting results, we consulted research teams that produced the articles in our scoping review to understand gaps between what researchers reported in publications and what they may have practiced in the field. While acknowledging the likelihood that researchers who chose to

participate in our survey were biased toward greater awareness, interest, or experience with report-back, our findings indicate that report-back is seemingly being conducted to a greater degree in practice than what articles may suggest, and decisions to discuss practices of results communication remain limited.

Researchers' decisions regarding report-back strongly reflected discussion of critical issues and debates in the literature. Key challenges identified included lack of guidance, navigating duty to report with associated potential of this to cause harm, scientific uncertainty, and inability to advise on mitigation of exposures.<sup>54</sup> Researchers' lack of training in risk communication as a challenge to report-back was a unique perspective raised in this survey and supports assertions that researchers need training in report-back techniques.<sup>55</sup>

Echoing one of the leading arguments against report-back, researchers who had not reported their results to subjects explained that their decision was guided by concerns with causing anxiety and discouraging breastfeeding as a result of mothers' knowledge of their body burdens. Interestingly, some researchers used this same argument of not wanting to discourage breastfeeding to justify report-back in explaining that they had shared results precisely to ensure this would be not misinterpreted and the right message for promotion of breastfeeding was disseminated. While the potential of negatively influencing breastfeeding behavior is overwhelmingly used as a reason

Box 3. Challenges with report-back processes

**Lack of guidance**

"It was difficult to have feedback in the papers published about how to proceed [with results communication]. Because of this we directly contacted some PIs (principal investigators)."

"Requests to ethical committees to advise [on how to communicate] were not returned."

**Navigating ethical dilemmas**

"A mismatch between duty to report and damage this communication may cause results in an ethical dilemma I do not have the answer for, nor am I equipped to investigate."

**Scientific uncertainties**

"We are still lacking tools to link association studies / mechanisms of action in vitro studies and individual risk assessment. We are also lacking efficient ways of reducing specific and overall environmental exposure."

**Lack of training**

"There is always a risk of not conducting properly the communication of risk. Many experts conducting studies in sensitive topics are not trained on risk communication."

against report-back, this tendency highlights how without clear evidence and consensus on the process of reporting results to subjects being studied, ethical considerations can be construed and acted upon differently depending on researchers' interpretations or stances on the issue.<sup>56</sup> IRBs are in the position to give guidance and oversight on research ethics, but they also rely on researchers and research findings to provide guidance on relatively unknown subject matters like ethics in report-back for biomonitoring studies.<sup>57</sup> Knowledge exchange on experiences among researchers and IRBs can indeed serve to mutually reinforce understanding of ethical dilemmas and best practices for report-back.

On the topic of not communicating findings to limit undue fear, one researcher in our survey further explained that their team was concerned with causing worry among subjects due to the community's level of understanding on the subject. Concern over this underlying driver of undue fear is not as widely reflected in the literature, as studies increasingly point to subjects' ability to understand and cope with topics in environmental contamination and individual biomonitoring results, regardless of socioeconomic background.<sup>58</sup> However, it is possible that this type of perspective is more prevalent than is evident in the literature, as there are limited platforms for researchers to raise such concerns free of judgment. This points to an urgent need for guidance and sharing of experiences among researchers, as preconceptions of context and capacity of subjects can reaffirm neocolonial relationships between researchers and subjects and neglect subjects as beneficiaries of research. Another justification raised in our survey for not conducting report-back was that data was collected and analyzed "purely for research purpose," thereby completely bypassing subjects from research benefits. The issue of who should be gaining from advancements in knowledge goes beyond the field of environmental health, as it points to the common oversight within global health research, whereby researchers are—or are perceived to be—the primary beneficiaries of data collected from research subjects and communities rather than as collaborators who work with communities in their

pursuit of a right to health such as by contributing to community-led advocacy for the reduction of exposure to environmental toxins.<sup>59</sup>

Moreover, global health research conducted among marginalized populations should not only understand community engagement as a strategy to achieve a human rights mandate by improving health or reducing hazardous exposures but also consider community engagement as a rights-based process with the potential to strengthen communities beyond the boundaries of the study or intervention.<sup>60</sup>

In fact, consideration of the scale that is being examined in studies can provide some guidance as to appropriate ethical approaches that should be taken. While HBM studies of contamination record contamination at the scale of the individual, the study of environmental pollutants is experienced at a population level—at the scale of community or larger area. In this regard, documenting the degree of contamination associated with patterns of exposure in settings where this has intensified can serve to signal a need for modification. In line with the concerns registered by indigenous studies scholar Eve Tuck that "contaminants research" should go beyond documentation of damage to necessarily consider the addressing of its source with inclusion of the agency of those affected, communication of population results to individuals and their communities warrants greater attention.<sup>61</sup>

Beyond ethical considerations that guide much of the decisions on report-back, logistical issues can also be obstacles for researchers to communicate results. Some survey participants mentioned losing contact with subjects, pointing to the broader issue of lack of guidance on approaches that would allow for follow up with subjects. For example, this guidance could cover the ins and outs of establishing good working relationships with subjects that naturally open a clear channel for report-back.<sup>62</sup> However, it can also be considered that lack of contact with subjects is symptomatic of scientists' lack of motivation to engage with subjects in this way.

Our study suggests that researchers conduct report-back of biomonitoring results to a greater degree in practice than what is reflected in their



publications. Decisions to conduct report-back and communication strategies are also informed by common debates and ethical considerations, indicating greater awareness on these issues among researchers than what can be gauged from their articles. In light of these findings, it is paramount that researchers are encouraged to share report-back approaches and experiences within their publications for the benefit of other researchers and IRBs. This begins with understanding whether researchers deem publications and journals in this field to be useful platforms for this type of discussion, a topic briefly explored through the survey component of this study. Furthermore, it is necessary to gain insight into potential constraints researchers face in publishing this type of information by investigating specifications and review processes of journals in environmental health and toxicology and attitudes of their editors on the appropriateness and value of publishing these topics within articles. Finally, we recommend the mainstreaming of guidance documents that compile evidence-based strategies on report-back. For example, the handbook produced by the Silent Spring Institute offers effective methods for reporting results, and crucially recommends inclusion of report-back evaluation that serves to improve knowledge on ethical practices in biomonitoring report-back and provide clarity on key ethical dilemmas.<sup>63</sup>

## Conclusion

HBM has changed the way we look at human interactions with the environment and the ways in which chemical pollution affects our bodies. However, opportunities presented by this technology must be explored with caution. Research that utilizes HBM can sometimes inadvertently label populations as deprived, damaged, or legacies of historical and present abuses, even when intended to bring about positive change.<sup>64</sup> This study indicates the need for readily available, evidence-based guidance on report-back of biomonitoring results to ensure that research in environmental health benefits affected populations through promoting greater awareness on pollutants and actions to

mitigate exposure. Based on the findings from this study, our team will ensure our report-back approach is documented and reflected within future publications to contribute to the evidence base and share our experiences with the wider international community. In this regard, our broader research team will continue to work closely and directly with local communities to connect communication of breast milk biomonitoring results with consideration of alternative solutions, in an effort to pursue the communities' right to a safe and healthy living environment while protecting and promoting the human right to breastfeeding.

## Acknowledgments

We would like to thank our Ecuadorian researcher and community partners as we continue to determine and pursue best practices for ethical research, and our survey participants for sharing their perspectives on biomonitoring report-back.

## References

1. D. Shelton, *Human rights, health and environmental protection: Linkages in law and practice*, A Background Paper for the WHO, Health and Human Rights Working Paper Series No. 1 (2002); P. J. Landrigan, R. Fuller, N. Acosta, et al., "The Lancet Commission on pollution and health," *The Lancet* 391/10119 (2018), pp. 462–512; W. A. Suk, H. Ahanchian, K. Asante, et al., "Environmental pollution: An under-recognized threat to children's health, especially in low- and middle-income countries," *Environmental Health Perspectives* 124/3 (2016), pp. A41–A45.
2. V. Yusa, M. Millet, C. Coscolla, et al., "Occurrence of biomarkers of pesticide exposure in non-invasive human specimens," *Chemosphere* 139 (2015), pp. 91–108.
3. World Health Organization, *Human biomonitoring: facts and figures* (Copenhagen: WHO Regional Office for Europe, 2015), pp. 1–88; A. Alves, A. Kucharska, C. Erratico, et al., "Human biomonitoring of emerging pollutants through non-invasive matrices: state of the art and future potential," *Analytical and Bioanalytical Chemistry* 406 (2014), pp. 4063–4088; K. Sexton, L. L. Needham, and J. L. Pirkle, "Human biomonitoring of environmental chemicals: Measuring chemicals in human tissues is the "gold standard" for assessing people's exposure to pollution," *American Scientist* 92/1 (2004), pp. 38–45.
4. R. Morello-Frosch, J. G. Brody, P. Brown, et al., "Toxic ignorance and right-to-know in biomonitoring results

communication: a survey of scientists and study participants,” *Environmental Health* 8/6 (2009); J. W. Nelson, M. K. Scammell, R. G. Altman, et al., “A new spin on research translation: The Boston Consensus Conference on Human Biomonitoring,” *Environmental Health Perspectives* 117/4 (2009), pp. 495–499.

5. J. M. Spiegel, J. Breilh, and A. Yassi, “Why language matters: Insights on the social determination of health through North-South collaborative research,” *Globalization and Health* 11/1 (2015), pp. 9–26; J. Breilh, “La determinación social de la salud como herramienta de transformación hacia una nueva salud pública (salud colectiva). [Social health determination as a tool of transformation towards a new public health (community health)],” *Rev. Fac. Nac. Salud Pública* 31/Suppl. 1 (2013), pp. S13–S27.

6. Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC), Social Sciences and Humanities Research Council of Canada (SSHRC), 2014. *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Ottawa, Canada: Secretariat on Responsible Conduct of Research; M. E. Morton Ninomiya and N. J. Pollock, “Reconciling community-based Indigenous research and academic practices: Knowing principles is not always enough,” *Social Science & Medicine* 172 (2017), pp. 28–36.

7. D. Shelton (see note 1); B. M. Meier and M. Labbok, “From the bottle to the grave: Realizing a human right to breastfeeding through global health policy,” *Case Western Reserve Law Review* 60/4 (2010), pp. 1073–1142; C. J. Chantry, A. Eglash, and M. Labbok, “ABM position on breastfeeding—revised 2015,” *Breastfeeding Medicine* 10/9 (2015), pp. 407–411.

8. A. Cordner and P. Brown, “Moments of uncertainty: Ethical considerations and emerging contaminants,” *Sociological Forum* 28/3 (2013), pp. 469–494; R. G. Stahl, T. S. Blingman, A. Guiseppi-Elie, et al., “What biomonitoring can and cannot tell us about causality in human health and ecological risk assessments,” *Human and Ecological Risk Assessment* 16 (2010), pp. 74–86; Morello-Frosch et al. (see note 4).

9. *Ibid.*

10. Morello-Frosch et al. (see note 4); J. G. Brody, R. Morello-Frosch, P. Brown, et al., ““Is it safe?” New ethics for reporting personal exposures to environmental chemicals,” *American Journal of Public Health* 97/9 (2007), pp. 1547–1554.

11. J. L. Ohayon, E. Cousins, R. Morello-Frosch, et al., “Researcher and institutional review board perspectives on the benefits and challenges of reporting back biomonitoring and environmental exposure results,” *Environmental Research* 153 (2017), pp. 140–149.

12. Ohayon et al. (see note 11); Morello-Frosch et al. (see note 4); M. Arendt, “Communicating human biomonitoring results to ensure policy coherence with public health recommendations: analysing breastmilk whilst protecting, promoting and supporting breastfeeding,” *Environment-*

*al Health* 7/Suppl. 1 (2008); J. S. LaKind, C. M. Berlin, J. L. Stokes, et al., “Lifestyle and polybrominated diphenyl ethers in human milk in the United States: A pilot study,” *Toxicological and Environmental Chemistry* 90/6 (2008), pp. 1047–1054.

13. Ohayon et al. (see note 11); R. Washburn, “Measuring personal chemical exposures through biomonitoring: The experiences of research participants,” *Qualitative Health Research* 24/3 (2014), pp. 329–344; J. G. Brody, S. C. Dunagan, R. Morello-Frosch, et al., “Reporting individual results for biomonitoring and environmental exposures: lessons learned from environmental communication case studies,” *Environmental Health* 13/40 (2014); C. Adams, P. Brown, R. Morello-Frosch, et al., “Disentangling the exposure experience: The roles of community context and report-back of environmental exposure data,” *Journal of Health and Social Behavior* 52/2 (2011), pp. 180–196; R. G. Altman, R. Morello-Frosch, J. G. Brody, et al., “Pollution comes home and gets personal: Women’s experience of household chemical exposure,” *Journal of Health and Social Behavior* 49/4 (2008), pp. 417–435.

14. S. R. Geraghty, J. C. Khoury, A. L. Morrow, et al., “Reporting individual test results of environmental chemicals in breastmilk: Potential for premature weaning,” *Breastfeeding Medicine* 3/4 (2008), pp. 207–213; N. Wu, M. D. McClean, P. Brown, et al., “Participant experiences in a breastmilk biomonitoring study: A qualitative assessment,” *Environmental Health* 8/4 (2009).

15. UNEP, *Global Chemicals Outlook—Towards Sound Management of Chemicals* (UNEP, 2013); Landrigan et al. (see note 1); S. Naidoo, L. London, H-A. Rother, et al., “Pesticide safety training and practices in women working in small-scale agriculture in South Africa,” *Occupational and Environmental Medicine* 67/12 (2010), pp. 823–828.

16. Morello-Frosch et al. (see note 4); R. Bhatia, B. Brenner, B. Salgado, et al., “Biomonitoring: what communities must know,” *Race, Poverty and Environment* 11/2 (2004), p. 56.

17. Ohayon et al. (see note 11).

18. Adams et al. (see note 13).

19. E. A. Emmett and C. Desai, “Community First Communication: Reversing information disparities to achieve environmental justice,” *Environmental Justice* 3/3 (2010), pp. 79–84; Morello-Frosch et al. (see note 4); D. Quigley, “Applying bioethical principles to place-based communities and cultural group protections: The case of biomonitoring results communication,” *Journal of Law, Medicine and Ethics* 40/2 (2012), pp. 348–358; Adams et al. (see note 13).

20. D. I. Saxton, I. Brown, S. Seguinot-Medina, et al., “Environmental health and justice and the right to research: institutional review board denials of community-based chemical biomonitoring of breast milk,” *Environmental Health* 14/90 (2015); R. Washburn, “The Social Significance of Human Biomonitoring,” *Sociology Compass* 7/2 (2013),

- pp. 162–179; P. Brown, J. G. Brody, R. Morello-Frosch, et al., “Measuring the success of community science: The Northern California Household Exposure Study,” *Environmental Health Perspectives* 120/3 (2012), pp. 326–331; Altman et al. (see note 13).
21. Ohayon et al. (see note 11); Saxton et al. (see note 20); Corder and Brown (see note 8); P. Brown, R. Morello-Frosch, J. G. Brody, et al., “Institutional review board challenges related to community-based participatory research on human exposure to environmental toxins: A case study,” *Environmental Health* 9/39 (2010), pp. 1–12; Morello-Frosch et al. (see note 4).
  22. D. I. Shalowitz and F. G. Miller, “Communicating the results of clinical research to participants: Attitudes, practices, and future directions,” *PLoS Medicine* 5/5 (2008), pp. 714–720; Corder and Brown (see note 8).
  23. Ohayon et al. (see note 11).
  24. Washburn (see note 20); S. A. Quandt, A. M. Doran, P. Rao, et al., “Reporting pesticide assessment results to farmworker families: Development, implementation, and evaluation of a risk communication strategy,” *Environmental Health Perspectives* 112/5 (2004), pp. 636–642; C. V. Fernandez, E. Kodish, and C. Weijer, “Informing study participants of research results: An ethical imperative,” *IRB: Ethics and Human Research* 25/3 (2003), pp. 12–19; M. D. Ramirez-Andreotta, J. G. Brody, N. Lothrop, et al., “Reporting back environmental exposure data and free choice learning,” *Environmental Health* 15/2 (2017); Brown et al. (see note 21); Adams et al. (see note 13); Morello-Frosch et al. (see note 4); Wu et al. (see note 14); Shalowitz and Miller (see note 22); Brody et al. (see note 10).
  25. Ohayon et al. (see note 11); Ramirez-Andreotta et al. (see note 24); Brody et al. (see note 13); Brown et al. (see note 20); Adams et al. (see note 13).
  26. Quigley (see note 19).
  27. Ohayon et al. (see note 11); Brody et al. (see note 13); Brown et al. (see note 20); Wu et al. (see note 14); Altman et al. (see note 13); Geraghty et al. (see note 14); Shalowitz and Miller (see note 22).
  28. Ohayon et al. (see note 11); Corder and Brown (see note 8); Morello-Frosch et al. (see note 4).
  29. Washburn (see note 20); A. D. Hernick, M. K. Brown, S. M. Pinney, et al., “Sharing unexpected biomarker results with study participants,” *Environmental Health Perspectives* 119/1 (2011); Brody et al. (see note 10); Quandt et al. (see note 24); Fernandez et al. (see note 24).
  30. Ohayon et al. (see note 11); Emmett and Desai (see note 19).
  31. Arendt (see note 12).
  32. Hernick et al. (see note 29); Morello-Frosch et al. (see note 4); Shalowitz and Miller (see note 22).
  33. Morello-Frosch et al. (see note 4).
  34. Brody et al. (see note 13).
  35. Brody et al. (see note 13); Hernick et al. (see note 29); Altman et al. (see note 13).
  36. L. Claudio, J. Gilmore, M. Roy, et al., “Communicating environmental exposure results and health information in a community-based participatory research study,” *BMC Public Health* 18/784 (2018).
  37. Fernandez et al. (see note 24).
  38. Ohayon et al. (see note 11); T. J. Downs, L. Ross, D. Mucciarone, et al., “Participatory testing and reporting in an environmental-justice community of Worcester, Massachusetts: a pilot project,” *Environmental Health* 9/34 (2010); R. L. Dunn and G. B. Carey, “Developing a biomonitoring educational pamphlet for potential participants in a breast milk biomonitoring study,” *Journal of Human Lactation* 26/2 (2010), pp. 183–186; Brody et al. (see note 10); Fernandez et al. (see note 24).
  39. Adams et al. (see note 13); Hernick et al. (see note 29); Emmett and Desai (see note 19); LaKind et al. (see note 12); Wu et al. (see note 14); WHO, *Fourth WHO-Coordinated Survey on Human Milk for Persistent Organic Pollutants in Cooperation with UNEP-Guidelines for Developing a National Protocol*, (Geneva: WHO, 2007).
  40. Brody et al. (see note 13); Downs et al. (see note 38); Dunn et al. (see note 38).
  41. Hernick et al. (see note 29); Wu et al. (see note 14); Shalowitz and Miller (see note 22).
  42. Corder and Brown (see note 8); Morello-Frosch et al. (see note 4).
  43. H. Arksey and L. O’Malley, “Scoping studies: Towards a methodological framework,” *International Journal of Social Research Methodology* 8/1 (2005), pp. 19–32; D. Levac, H. Colquhoun, and K. K. O’Brien, “Scoping studies: advancing the methodology,” *Implementation Science* 5/69 (2010).
  44. D. Moher, A. Liberati, J. Tetzlaff, et al., “Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement,” *Annals of Internal Medicine* 151/4 (2009), pp. 264–269.
  45. Ohayon et al. (see note 11).
  46. X. Rojas-Squella, L. Santos, W. Baumann, et al., “Presence of organochlorine pesticides in breast milk samples from Colombian women,” *Chemosphere* 91 (2013), pp. 733–739; J. Wasser, T. Berman, L. Lerner-Geva, et al., “Biological monitoring of Persistent Organic Pollutants in human milk in Israel,” *Chemosphere* 137 (2015), pp. 185–191.
  47. Rojas-Squella et al. (see note 46).
  48. Ibid.
  49. Rojas-Squella et al. (see note 46); Wasser et al. (see note 46); C. Guerranti, G. Perra, S. Corsolini, et al., “Pilot study on levels of perfluorooctane sulfonic acid (PFOS) and perfluorooctanoic acid (PFOA) in selected foodstuffs and human milk from Italy,” *Food Chemistry* 140 (2013), pp. 197–203; P. O. Darnerud, M. Aune, L. Larsson, et al., “Levels of brominated flame retardants and other persistent organic pollutants in breast milk samples from Limpopo province, South Africa,” *Science of Total Environment* 409 (2011), pp.

4048–4053; R. D. Behrooz, A. Esmaili-Sari, F. E. Peer, et al., “Mercury concentration in the breast milk of Iranian women,” *Biological Trace Element Research* 147 (2012), pp. 36–43; S. Gebremichael, T. Birhanu, and D. A. Tessema. “Analysis of organochlorine pesticide residues in human and cow’s milk in the towns of Asendabo, Serbo and Jimma in South-Western Ethiopia,” *Chemosphere* 90 (2013), pp. 1652–1657.

50. Rojas-Squella et al. (see note 46).

51. Guerranti et al. (see note 49); Darnerud et al. (see note 49); Behrooz et al. (see note 49); Gebremichael et al. (see note 49).

52. Ohayon et al. (see note 11); Cordner and Brown (see note 8).

53. LaKind et al. (see note 12).

54. Ohayon et al. (see note 11); Cordner and Brown (see note 8); Morello-Frosch et al. (see note 4); Brody et al. (see note 10); Stahl et al. (see note 8).

55. Brody et al. (see note 13).

56. Dunn et al. (see note 38); Ohayon et al. (see note 11); Arendt (see note 12) LaKind et al. (see note 12).

57. Ohayon et al. (see note 11).

58. Adams et al. (see note 13); Quandt et al. (see note 24).

59. A. Yassi, J. Breilh, S. Dharamsi, et al., “The Ethics of Ethics Reviews in Global Health Research: Case Studies Applying a New Paradigm,” *Journal of Academic Ethics* 11/2 (2013), pp. 83–101; A. Costello and A. Zumla, “Moving to research partnerships in developing countries,” *BMJ* 321 (2000), pp. 827–829; J. M. Spiegel, J. Breilh, and A. Yassi (see note 5).

60. A. R. Coates, S. del Pino Marchito, and B. Vitoy, “Indigenous child health in Brazil,” *Health and Human Rights Journal* 18/1 (2016), pp. 221–234.

61. E. Tuck, “Suspending damage: A letter to communities,” *Harvard Educational Review* 79/3 (2009), pp. 409–427.

62. Downs et al. (see note 38).

63. S. C. Dunagan, J. G. Brody, R. Morello-Frosch, et al., *When pollution is personal: Handbook for reporting results to participants in biomonitoring and personal exposure studies* (Newton, MA: Silent Spring Institute, 2013).

64. Tuck (see note 61).

## Appendix

### *Survey questions*

1. Did your team directly communicate results of contamination levels to research subjects?
  - a. Yes
  - b. No
2. If results were communicated, how (e.g., report, brochure, workshop) and to whom (e.g., mothers of community involved) was this conducted?
3. What type of results were reported to participants?
  - a. Individual-level results (samples analyzed and results reported individually)
  - b. Aggregate-level results (samples analyzed individually and group results reported)
  - c. Pooled results (samples mixed for analysis and single result reported)
  - d. Other (please specify)
4. Why did your team choose this method of communication?
5. In retrospect, would you have followed any other method? Why?
6. Was your experience in communicating results to research subjects reported anywhere?
7. What were the considerations behind communicating or not communicating results to research subjects?
8. Academic journals in environmental health-related fields (e.g. toxicology and biomonitoring) are a useful platform to discuss ethical concerns regarding HOW contamination levels are communicated to research subjects.
  - a. Strongly agree
  - b. Agree
  - c. Neutral
  - d. Disagree
  - e. Strongly disagree
9. In contamination studies, whom do you feel is best positioned to communicate research findings to research subjects?
  - a. Research team
  - b. Municipal/community worker
  - c. Health care worker
  - d. Other (please specify)
10. In your experience and within your field, what are the challenges to results communication and best practices for disclosure?





# Ethical Considerations for Disseminating Research Findings on Gender-Based Violence, Armed Conflict, and Mental Health: A Case Study from Rural Uganda

JENNIFER J. MOOTZ, LAUREN TAYLOR, MILTON L. WAINBERG, AND KAVEH KHOSHNOOD

## Abstract

Gender-based violence (GBV) is a major public health problem that is exacerbated in armed conflict settings. While specialized guidelines exist for conducting research with GBV, guidance on disseminating findings from GBV research is scant. This paper describes ethical considerations of designing and disseminating research findings on GBV, armed conflict, and mental health (including alcohol misuse) in conflict-affected settings in Northeastern Uganda. Following completion of two research studies, we conducted a half-day dissemination meeting with local community professionals (n=21) aged 24 to 60. Attendees were divided into small groups and given a quiz-style questionnaire on research findings to prompt discussion. Two primary ethical tensions arose. One ethical consideration was how to disseminate research findings equitably at the participant level after having taken care to collect data using safe and unharmed methods. Another ethical issue concerned how to transparently share findings of widespread problems in a hopeful and contextualized way in order to facilitate community response. We recommend planning for dissemination a priori, engaging with partners at local levels, and grounding dissemination for action in evidence-based practices.

---

JENNIFER J. MOOTZ is a research scientist at Columbia University Department of Psychiatry in New York, NY, USA.

LAUREN A. TAYLOR is a doctoral candidate at Harvard Business School in Boston, MA, USA.

MILTON L. WAINBERG is professor of clinical psychiatry at Columbia University Department of Psychiatry in New York, NY, USA.

KAVEH KHOSHNOOD is associate professor of public health at Yale University in New Haven, CT, USA.

Please address correspondence to the authors c/o Jennifer Mootz. Email: [jennifer.mootz@nyspi.columbia.edu](mailto:jennifer.mootz@nyspi.columbia.edu).

Competing interests: None declared.

Copyright © 2019 Mootz, Taylor, Wainberg, and Khoshnood. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted noncommercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

## Background

### *Gender-based violence and armed conflict*

Gender-based violence (GBV), identified as one of the most challenging and widely permeating human rights issues today, affects one-third of women worldwide.<sup>1</sup> The United Nations has defined GBV as any act of psychological, physical, or sexual harm to women and girls.<sup>2</sup> Some of the highest rates of GBV occur in sub-Saharan Africa. In some countries in eastern Africa, for instance, almost three-fourths of women report experiencing some type of partner-perpetrated violence in their lifetime.<sup>1</sup> Exposure to GBV presents a tremendous public health problem through numerous physical, mental, and intergenerational deleterious effects.<sup>3</sup>

Armed conflict, between or within nations or among civilian factions, exacerbates GBV in communities.<sup>4</sup> With critical breakdowns in legal and social infrastructures, impunity for perpetrators increases.<sup>5</sup> Most victims are women and adolescent girls who experience GBV through sexual assault by combatants and soldiers, increase in human trafficking, and use as expendable bodies in conflict.<sup>6</sup> There are also documented increases in household GBV in the form of intimate partner violence (IPV): intimate partner behaviors that cause physical, sexual, or psychological harm.<sup>7</sup> While the relation between armed conflict and GBV, including IPV in households, has been observed across several contexts, little is known about mechanisms through which armed conflict affects GBV and IPV specifically.<sup>8</sup> The first author has examined mechanisms between armed conflict and GBV in Northeastern Uganda and, in this paper, we discuss some of the ethical challenges associated with designing GBV research and disseminating findings.

### *Ethical principles and gender-based violence research*

Traditional bioethical approaches demand an assessment of the study on the basis of four principles: beneficence, non-maleficence, autonomy, and justice. These norms are considered guideposts for moral agents working in both health care delivery and research. The American Psychological Association's

guidelines include an additional mandate for integrity, honesty, and truthfulness in scientific research and accurate representation of facts.<sup>9</sup> Ezekiel Emanuel and colleagues provided new guidance to clinical researchers in 2001 in their highly cited article *What makes clinical research ethical?*<sup>10</sup> Therein, they lay out seven necessary-and-sufficient requirements: value, scientific validity, fair subject selection, favorable risk-benefit ratio, independent review, informed consent, and respect for enrolled subjects.

The need for researchers to protect research participants' confidentiality has been well-established in research ethics literature. This obligation to protect confidentiality can come into tension with the Declaration of Helsinki's stipulation that researchers make publicly available the results of their human participant research. Myriad papers offer researchers guidance on safeguarding data collected from human subjects throughout the research process, including extensive and, at times, repeated informed consent processes; sophisticated means of anonymizing data; and design choices that favor large sample sizes so as to protect individual identities.

Ethical complexities can be amplified in cases where research is being conducted on violence against women. This area of inquiry has been identified as one deserving a special class of protections—for instance, it is considered best practice to recruit women for observational research related to GBV with a “vague first contact,” in which the research is described to potential participants as a general study related to health, rather than specifically about GBV.<sup>11</sup> Recruitment of women who have been victims of assault can feel coercive.<sup>12</sup> Dissemination of a community-based HIV prevention project aimed at women engaged in survival sex proved equally challenging, as researchers and advocates alike feared that the dissemination of study results could further stigmatize an already stigmatized group.<sup>13</sup>

In spite of these concerns, investigators with a goal of eliminating GBV have been repeatedly called to “translate and disseminate their work to people who can use it to make change.”<sup>10</sup> The challenges of

disseminating research related to GBV has generated limited scholarly attention, most often as part of larger projects describing ethical and safety challenges inherent in conducting research on domestic violence, GBV, or other types of violence against women. Rachel Jewkes et al.'s treatment of the topic in 2000 argued that given the profound safety risks involved in GBV research in Southern Africa, the only rationale for conducting such research is the potential to create on-the-ground policy and culture change.<sup>14</sup> In 2001, the World Health Organization (WHO) published seminal ethical guidelines for conducting research with violence against women in the report *Putting women first: Ethical and safety recommendations for research on domestic violence against women*.<sup>15</sup> These guidelines proposed eight recommendations: ensuring safety of participants, designing methodologically-sound research to minimize underreporting, protecting confidentiality of participants, training and supporting research team members, building in ways to reduce participant distress caused by the research, training fieldworkers to refer and provide support in settings with low infrastructure, ensuring results "are properly interpreted" and used to develop policy and programming, and including violence questions in other lines of research only if these ethical requirements are met. Similar guidelines have been reiterated in the literature in the nearly two decades since.

### *Ethics of research dissemination*

The impetus for researchers to disseminate results has more recently gained traction in health sciences generally and global health research in particular. Various ethical underpinnings for this obligation have been proposed, though none appears to be standard. Standard bioethics analyzes ground the obligation to disseminate research in a respect for persons or justice.<sup>16</sup> Zlotnik et al. argued that these bases are insufficient to capture the unique connection between what research subjects offer and the specific benefit they are owed in return: information. In place of respect for persons or justice, they ground the obligation to disseminate in an overarching goal of researchers to be accountable, defined

as "answerability for a responsibility conferred."<sup>17</sup> Dauda and Dierickx, for instance, grounded the obligation to disseminate results in a broader responsibility for researchers to share benefits, defined as "giving a portion of advantages or profits derived from the research to resource providers in order to achieve justice in exchange."<sup>18</sup> They, and other authors writing on benefit sharing, cited the Universal Declaration of Bioethics and Human Rights as a source text for the duty to benefit-share.<sup>19</sup> In a qualitative study of the perceptions of research participants regarding dissemination of research findings, respondents confirmed previous theorists' rationales for dissemination, reporting that they felt a sense of ownership over the findings.<sup>20</sup> They also overwhelmingly favored receiving updates on progress throughout, rather than at the conclusion of the research only.

The Council for International Organizations of Medical Science (CIOMS), in collaboration with WHO, released 25 guidelines for international ethical guidelines for health-related research in 2016.<sup>21</sup> Guideline 7, "Community Engagement," specifies that researchers should engage potential "participants and communities in a meaningful participatory process that involves them early in a sustained manner" throughout the research process, including dissemination. Guideline 23, "Requirements for Establishing Research Ethics Committee and Their Review Protocols," returns to the theme of dissemination. It states that researchers are accountable for making their results publicly available and accessible to the lay public and communities where research was conducted. Guideline 7 of the WHO *Putting women first* document concerns dissemination of findings and suggests that researchers have a "moral obligation" to provide feedback to communities and inform policy. Specific dissemination recommendations are to partner with local groups from the outset to inform dissemination procedures as members of an advisory committee and infuse findings into existing policy and programming. Moreover, Guideline 7 suggests that researchers ensure that findings do not stigmatize or exacerbate negative stereotypes of groups based on ethnic and social identification.

In 2016, WHO developed a companion guide to the 2001 *Putting women first*, adding a new set of recommendations for intervention research. The dissemination guideline, underpinned by biomedical research ethics, remained mostly unchanged with the exception of recommendations that highlight the ethical mandate to consider scale-up and sustainability of effective interventions.<sup>22</sup>

Enthusiasm for dissemination of research results has appeared particularly strong within the community-based participatory research (CBPR) literature, where engagement of stakeholders and communities at all phases of research is widely endorsed. Much of CBPR dissemination literature, however, comes out of research and community partnerships developed in the United States and Canada. A systematic review of dissemination practices in CBPR research ( $n=101$ ) in the United States found that half of the studies reported dissemination beyond publication. Most researchers (77%) disseminated findings via meetings and media coverage (~50%). Lesser-used formats were posters and flyers, phone calls, and word of mouth. This review included follow-up surveys with researchers to understand how they framed dissemination within CBPR practice. Content analysis identified five themes:

- dissemination is valuable as a component of CBPR and in the maintenance of researcher-community relationships;
- dissemination is affected by myriad goals of diverse stakeholders;
- cultural differences are important variables to consider for effective dissemination, as are time and resources; and
- dissemination is imperative for sustainability.<sup>23</sup>

Researchers in the United States have outlined the need to embrace CBPR for numerous reasons, including a potential strengthening of future research because of feedback about research processes from stakeholders.<sup>24</sup> A CBPR study with indigenous communities in rural Alaska involved a carefully designed dissemination process where-

in community-wide presentations were held. These presentations were followed by community planning group meetings, wherein community members discussed implications of the findings.<sup>25</sup> Theoretical frameworks providing a full account of the rationales and benefits of community and stakeholder engagement are emerging, as is the evidence base for what type of research behaviors constitute effective stakeholder engagement.<sup>26</sup>

The two ethical imperatives—the need to safeguard human subjects’ confidentiality and the need to disseminate research results—can conflict. This conflict has been considered most concertedly in the genomics and bio-banking literature, where new technologies are enabling specimen re-use and re-identification in ways that were previously impossible.<sup>27</sup> In the global health literature, the emphasis on CBPR and stakeholder engagement is prompting different concerns about how researchers can maintain their commitments to both confidentiality and dissemination. While much of the treatment of these ethical dilemmas in the genomics and biobanking literature suggests providing upfront clarity in the protocol about results notification, the protocol is often not fully defined *ex ante* in instances of CBPR fieldwork.

This tension to follow conflicting ethical principles and other concerns has only begun to be described in the global health literature. Two recent papers offer candid description of challenges in disseminating sensitive findings. Turcotte-Tremblay and McSween-Cadieux described challenges disseminating findings confidentially following fieldwork on improving health systems in West Africa.<sup>28</sup> In particular, their concerns related to professional repercussions for interviewees whose supervisors discovered their identities. Stepping back from their own experience, the authors suggested four environmental factors that interact and can influence potential for identification of confidential research participation: hierarchical structure, small milieu, immersion in a few sites, and vested interests of decision makers. Baylor et al. similarly described a conscientious dissemination process wherein they gathered more than 400 Ugandan participants in a study of people living



with HIV for a ceremony modeled on a local wedding for a dissemination conference.<sup>29</sup> Members of the research team discussed confidentiality concerns with participants over the phone when inviting participants to the event. Most participants were willing to attend despite the inherent loss of confidentiality to other participants.

## Our contribution to ethics of disseminating GBV research

Despite recognition of the need for specialized ethical guidelines when conducting research on GBV, recommendations for disseminating research findings have been less developed. To our knowledge, no recommendations exist for disseminating research on GBV in conflict-affected populations. In this paper, we share our experiences of designing and disseminating research findings on these difficult topics, including the risks and ethical considerations. Rather than being prescriptive, we describe our ethical considerations with the aim of stimulating discussion towards the development of recommendations for the identification and response to ethical issues in GBV research in underserved and marginalized contexts.

### *Study setting*

We have conducted two research projects in the Teso subregion of Northeastern Uganda. Teso borders Karamoja, where cattle raiding (violent looting of cattle and other livestock) among subtribes of the pastoralist nomadic Karamojong was highly ritualized and commonplace. When Tanzania overthrew Idi Amin's army in 1979, many of Amin's soldiers fled and left behind their AK-47s. One of the Karamojong subtribes acquired these weapons, which quickly escalated the violence associated with cattle raids and had other repercussions, such as inflated bride price (a man's payment of cattle to a woman's family). With little international notice, the Karamojong subtribes' cattle raiding spread to Teso.<sup>30</sup> The raiding induced large-scale displacement into camps protected by the Ugandan government army. While this was transpiring, another conflict between the Lord's Resistance Army and the Ugan-

dan government impacted the region when the Lord's Resistance Army invaded Teso in 2003. As was the case in the conflict in Northern Uganda, the combatants perpetrated widespread atrocities against civilians, including abduction of children, murder, looting and destruction of property, and sexual assault.<sup>30</sup> Many communities, especially those along the border between Teso and Karamoja, remain militarized, with government soldiers positioned there to protect against cattle rustling, despite the Ugandan government's disarmament program that began in Karamoja in 2006.

### *Study 1: Community-partnered qualitative study*

The first research project was a qualitative project based on collaboration between the first author, a local nonprofit organization, and a community volunteer group. Aiming to understand how the community conceptualizes GBV and how armed conflict impacts GBV, the first author and collaborators conducted focus groups and in-depth interviews ( $n=77$ ) with community members aged 9 to 80, obtaining both assent for minors and consent from caregivers and adults. This study resulted in the development of a socio-ecological conceptual model that describes four pathways between armed conflict and GBV.<sup>31</sup> Community participants described one direct pathway, which occurred when Karamojong warriors sexually assaulted women and girls during the cattle raids. The three indirect pathways were complex, involved numerous variables, and initiated by 1) looting of property, 2) increased militarization of communities, and 3) death of civilians. The younger participants' input was integral to constructing these pathways. For example, according to adolescent girls, increased militarization of communities put them at risk for 1) early marriage with payment of bride price, or 2) sexual assault, because soldiers have income and the community members mostly subsist off agriculture. Every focus group and individual interview highlighted problematic male alcohol misuse in relation to household IPV, noting that male alcohol misuse interacted with husbands' perceptions that their wives were denying them something (such as food or sex) or challenging their

authority in some way.

### *Study 2: Population-based mixed methods study*

The second research project quantitatively tested the most commonly described indirect pathway in Study 1's socioecological conceptual model: men's poor mental health experiences as a result of looting, loss of livelihood, and other interacting factors. Because the community participants in Study 1 had identified IPV as the most ubiquitous form of GBV in their settings, the first author specified the dependent variable to focus on IPV. Study 2 involved a population-based survey across three districts in Teso to understand the scope of the problems of exposure to armed conflict, male alcohol use, and IPV. Using structural equation modeling, this study tested a pathway between exposure to armed conflict, men's alcohol misuse and socioeconomic status, and IPV, which demonstrated an excellent fit with the population data. The association between men's alcohol misuse and IPV was moderated by decision-making practices of couples (that is, alcohol misuse associated with violence for couples who had inequitable decision-making for women's health care).<sup>32</sup>

### Dissemination method

In August 2017, we returned to Uganda to share the findings of these two projects in a commonly used dissemination meeting format.<sup>23</sup> As is noted in the WHO guidelines on researching GBV, partnerships are key. We convened a dissemination committee that consisted of three local, bilingual (English/Ateso) research assistants who had collected and helped analyze data in the population-based study, and a community liaison, a program manager with a local NGO who had experience with community advocacy organizing, development work, and GBV programming. Our local partners identified key community members from the three surveyed districts to participate in a half-day dissemination meeting held in a central location. Community participants received compensation for travel, attendance, lunch, and refreshments. Invited attendees represented various community sectors,

such as locally elected political representatives; specialized police personnel who respond to family violence; personnel from nonprofit organizations with programming in mental health, development, GBV, and peace-building; clergymen; and community volunteers. A dissemination committee member traveled by motorbike to deliver in-person invitations to identified key community officials.

### *Meeting procedure*

We initiated the dissemination meeting by asking attendees to complete a brief survey with questions about basic demographics, professional title and experience, hopes for learning and sharing, and permission to publish anonymous contents of our meeting. Following introductions and an opening prayer, the first author described how the researcher and local partner collaboration developed, as well as the data collection procedures of the two research studies. A representative from the dissemination committee joined each group to facilitate discussion. Following small group discussion, we reconvened as a larger group. Each group had an opportunity to share main discussion points from their small group, after which the first author shared the research findings and then facilitated discussion with the larger group on any topics where groups expressed surprise, difficulty understanding, or perceptions of problems that were incongruent with findings. Per feedback from facilitators and observation, all groups were lively, and members participated actively.

### *Descriptive characteristics of meeting attendees*

The dissemination meeting included 21 attendees: 16 men and 5 women. The imbalanced representation of men parallels the larger sociocultural gendered trend for professional employment. The ages of respondents ranged from 24 to 60 with an average of 39.95 years. The majority of respondents (n=15) identified their ethnicity as Etesot. Other ethnicities were Gishm, Kumum, Largo, Samia, Etero, and Kimmam (n=1 each).

### Ethical considerations

While attention to all ethical principles during various stages of research is crucial, we found that ethical principles became more or less prominent based on the stage of research. Ethical considerations for data collection conflicted with those for dissemination, producing tensions described below.

### *Beneficence/nonmaleficence and distributive justice*

The driving ethical agenda for data collection was beneficence (do good) and nonmaleficence (do no harm). Maintaining beneficence meant conducting research that could not only build knowledge but also inform the development of interventions that benefit local communities, in particular women and girls who had experienced GBV in these settings.<sup>33</sup>

Practicing nonmaleficence signified conducting the research in a way that would not induce or exacerbate violence or mental distress: Ensuring the safety of participants and the research team was a primary emphasis. The research studies assessed three areas of notable ethical concern in terms of physical and psychological safety: exposure to armed conflict, exposure to IPV, and mental health symptoms and experiences (including suicidal ideation). These areas required the development of targeted safety protocols, a challenge in rural communities situated in one of the poorest countries in the world, where decades of armed conflict has impoverished communities and weakened infrastructure. For example, no mental health services exist in these rural areas and participants would have to finance and travel long distances to receive care for imminent suicidal ideation or mental health problems. Moreover, in these communities, due to patriarchal laws and sociocultural practices, women have few rights to children and land. Separation of families is highly stigmatized, and no shelters or temporary subsidized housing exist for women who experience IPV. The development of safety protocols accounting for local realities occurred in consultation with global experts, local partners, and scientific literature. Resulting safety procedures included intensive training of the research team to evaluate risk level through a series of assessment questions, and establishment of a

mobile team that could respond to women at high risk of self-harm or partner violence.

To ensure safety, it was critical to maintain confidentiality of participants and the research team. The methods of Study 1 were focus groups and individual interviews. Thus, to reduce potential problems associated with confidentiality, Study 1 did not inquire about personal experiences with these problems and instead framed questions about what participants observed in their communities. Yet, some participants shared personal experiences and, in anticipation of that eventuality, the first author advised focus group members to keep the contents of the discussion confidential and reminded them of the limits to confidentiality given the format of focus groups.

Study 2, on the other hand, involved collecting data at the individual level. In an effort to do no harm and knowing that surveying both men and women could be problematic, the first ethical decision point was who to survey. Given that men might underreport IPV or become agitated when asked about it, the first author elected to survey women. When introducing the study to community officials and participants, in accordance with the WHO guidelines, the research team masked the purpose of research as a survey on women's health. Another precaution, also informed by the WHO guidelines, was to train research assistants to pause the interview or change the subject to benign conversation if privacy was compromised during the interview process. Occasionally, practicing nonmaleficence required anticipating indirect pathways of potential harm. For instance, because respondents in Study 1 had identified male alcohol misuse as a major problem in the area and as strongly related to IPV, there was concern that male partners might take women's compensation funds and spend it on alcohol, thereby indirectly exacerbating the problem. Thus, the local research team determined that soap, a basic necessity, would be useful compensation for women and was less likely to be taken. Finally, safety procedures to protect the research team included traveling in pairs and in-depth debriefing sessions following various forms of data collection.

When the research transitioned into the

dissemination phase following data collection and analysis, the ethical principle of distributive justice gained prominence. The goal of distributive justice is to ensure that no discrete group of people disproportionately bears the risks of research, and that all have equal access to the benefits of research. Balancing this principle with beneficence and nonmaleficence proved challenging. Working to equitably distribute information learned from this research, an ethical consideration was determining the level at which to disseminate research findings (for example, population, community, and/or media). While the first author had intentionally employed mixed methods to highlight marginalized women's voices, it was an ethical dilemma to work out how to deliver findings on GBV at a grassroots, population level, so the findings would benefit and not harm participants. One possibility, for example, was to facilitate open community events and professionals and nonprofessionals to attend. However, in consultation with the dissemination committee and local experts, this approach was deemed too risky. Given that the purpose of the survey had been masked for safety and the research team followed up the surveys with two home visits to women who had endorsed experiencing physical or sexual IPV, there was concern that participants would be identifiable and subsequently at risk for harm if the communities were apprised of the methods and results. These risks informed our decision to include community-based professionals only.

### *Integrity and beneficence: Dissemination for action*

Community-partnered approaches such as ours aim to be collaborative, involve local capacity building, embolden partners, and balance action with research.<sup>34</sup> These cooperative approaches are meant to benefit local communities through action, information dissemination, and sharing power.<sup>34</sup> In the data collection phase, the impetus for beneficent research was to design a rigorous study that contributes to the literature base. In the dissemination phase, an ethical issue became how to disseminate findings transparently and with integrity about

difficult issues. This dissemination needed to follow the ethical principle of beneficence by facilitating change, in a way that would not shut down community partners.

Community-partnered approaches stress the importance of operating from a strengths-based perspective. While Studies 1 and 2 asked about community strengths and coping, the main research questions evaluated problems of armed conflict, IPV, and mental health outcomes. Findings revealed high rates of IPV, exposure to armed conflict, male alcohol misuse, and mental health problems. These findings showed that IPV was mostly perpetrated by male partners in the household. In a highly patriarchal setting, it was necessary to consider carefully the ramifications of identifying men as perpetrators. Study 1, for instance, revealed a common perception among men that women were to blame for driving violence in the home. Furthermore, research participants identified unjust legal and protection practices that favored men (most dissemination meeting attendees were male) and permeated formal institutions (some of which were represented in the dissemination meeting). Key informants described community resistance as one of their main challenges in raising awareness about IPV. The ethical dilemma became how to share these problems that were deeply entrenched in larger sociopolitical conditions.

Understanding that these issues had the potential to evoke resistance, it was of central importance to select a framework within which to build a message about findings. Disseminating findings beneficently meant avoiding pathologizing communities and assigning meritocratic responsibility for problems identified in the research. Thus, to conceptualize the dissemination process, we leveraged the framework of historical trauma to contextualize the findings in historical and larger sociopolitical conditions. The concept of historical trauma, which grounds current collective distress in past suffering, emerged after immersed clinical work with American Indian populations in the United States.<sup>35</sup> We used the comprehensive socioecological model to conceptualize problems evaluated in Studies 1 and 2. Thus, we could follow the framework of historical

trauma by demonstrating connections between community exposure to armed conflict inflicted by outsiders to the community and ongoing problems faced in communities and homes. We concluded our dissemination meeting by eliciting discussion about community strengths that could prevent and respond to these problems.

In addition to operating from a contextualized framework, we also designed the methods of dissemination with beneficence through action in mind. Effective collaborative work involves bidirectional dialogue about research findings.<sup>36</sup> Despite the importance of dialogue among researchers and community partners that is equitable, scarce literature exists describing best practices for engagement of community partners, especially those communities who have few resources and have experienced injustices through colonization and other forms of armed conflict.

Guided by the ethical imperative to promote bidirectional dialogue for change, instead of making a lecture-style passive format, we used a variety of active learning strategies to prompt discussion in small group format. We selected core quantitative and qualitative findings for use in quiz-style questions. Small groups worked through items intentioned to elicit dialogue and engage them in diverse mental exercises. For example, to facilitate discussion on the scope of these problems, the dissemination committee asked multiple choice questions about prevalence rates. One question asked: "How many men in our study drank alcohol daily? a. 60%; b. 30%; c. 5%." The small groups deliberated and came to consensus about their answers. Another type of question was designed to stimulate discussion about the deeper meanings behind sensitive results. For instance, "A young boy said this: 'When dad goes to drink, it tends to poison him.' What do you think this boy was talking about?"

These participatory methods allowed for several insights about the research findings, all of which were informative for the development of an applied intervention. For example, regarding prevalence of male alcohol misuse, all groups thought there should have been a response item that was above 60% (the highest rate listed) and closer to

80%. This discrepancy between attendees' perceptions and our findings prompted discussion about whether we had accurately assessed male alcohol use and the understanding that it was likely even more problematic than found in the research. We also learned valuable information about social norms of alcohol use. Attendees described rituals where children as young as two years old were introduced to alcohol. They also highlighted the important role that alcohol played in maintaining male social networks. Therefore, reducing alcohol consumption among men could isolate them from their peers, while research is clear that social support and relationships are important for optimal mental health.<sup>37</sup> Moreover, women brew and sell most alcohol. Many male partners have been killed in conflict and few other options exist for women to sustain their families. Thus, a community-based intervention that effectively decreased alcohol consumption could deplete the already tenuous incomes of women who sell alcohol.

Globally, mental health problems are stigmatized. Deciding again how to disseminate these findings without pathologizing women or explicitly implicating men was another ethical decision-making point. The community participants (Study 1) and women (Study 2) had described numerous deleterious mental health outcomes as a result of IPV. To illustrate relations among these mental health problems and IPV, analysts in the United States designed a conceptual figure of boxes and directional arrows. We asked dissemination meeting attendees to engage in a similar mental exercise. This resulted in ways of modeling relations among these problems from local perspectives. One small group, for instance, conceptualized women's mental health experiences relating to IPV from a more organic perspective than US analysts had depicted. They articulated that female survivors of IPV and their mental health experiences might be conceptualized as a tree. The violence women experience signifies the root system that sustains the tree, and the leaves and foliage represent symptoms that cyclically interact by feeding back into the soil. This locally grounded perspective has informed how the framing of future interventions can illustrate IPV's



deleterious mental health outcomes in a contextualized way.

## Recommendations

Several recommendations follow from wrestling with the ethical considerations involved in disseminating findings on armed conflict, GBV, and mental health in a low-income country. First, planning to disseminate findings beyond publication for academic audiences should occur *a priori* to the initiation of research. Initial plans should include funding for dissemination in the research budget and building dissemination into grant proposal timelines. While the role of funders in providing incentives or requirements to disseminate findings beyond publication has yet to be explored, procuring funding for dissemination meetings and events is especially important when working with low-resourced, marginalized communities that have endured decades of armed conflict.<sup>38</sup> In addition to researcher travel, costs to consider are payment for dissemination committee members' time and work, meeting venue, refreshments and meals, and travel costs for attendees, among others.

Second, engaging in meaningful research-community partnerships at the local level is key. National populations are heterogeneous with differences between urban and rural settings. In Uganda, for instance, numerous ethnic groups and languages exist.<sup>39</sup> To account for these variabilities, consultation and collaboration should include liaisons at the most local level possible. Initially overlooked for inclusion in the dissemination meeting, we advocated for inviting community volunteers who were unaffiliated with formal institutions and had less training and education. Moreover, it would be helpful to first determine with local partners the level at which data will be disseminated. If the first author had anticipated wanting to disseminate findings at the participant level *a priori*, for instance, she could have included open-ended questions for participants about their ideas for dissemination, thereby broadening the participatory scope of the study.

As a component of the research plan, evidence

and best practices should inform dissemination methods with an ethical goal of doing good through action. Evidence-based practices in pedagogy, such as methods of teaching with active learning strategies, should guide design of dissemination activities. Models of behavior change, such as the transtheoretical model and associated techniques, have been used successfully in other training and implementation activities.<sup>40</sup> Methods of designing participatory logic models and theory of change should be considered. The development of such models can start with identifying desired outcomes and move backward to determine what is needed to achieve those outcomes. Finally, the use of contextualized frameworks, such as historical trauma, should guide researcher-community partners in communicating findings so as to facilitate change and reduce resistance to the message.

## Disseminating GBV research and human rights

While we did not resolve ethical dilemmas inherent in these research studies by adhering to a human rights framework, we recognize retrospectively that we had, in fact, made ethical decisions that favored a human rights perspective. Research-oriented ethical guidelines, such as the Declaration of Helsinki or the Council for International Organizations of Medical Sciences (CIOMS), have generally been remiss in discussing practical considerations for dissemination of GBV research findings. However, we have discovered that the aims of human rights documents, such as the Universal Declaration of Bioethics and Human Rights, provide guidance that was missing in bioethics literature. Article 4 of the Universal Declaration of Bioethics and Human Rights (optimize benefit and minimize harm) parallels beneficence and non-maleficence mandated by ethical guidelines. Other articles, such as Article 3, which focus on human dignity and human rights, provide more applicable guidance by highlighting the importance of prioritizing individual rights and freedoms over scientific benefits to society at large. We recognize the principle of dignity because one of our challenges was protecting individual

rights and freedoms of participants while facilitating equitable access to scientific findings through dissemination. Article 8 on respect for human vulnerability and personal integrity is likewise relevant, as it stresses the importance of respecting and protecting vulnerable individuals and groups and their personal integrity. In accordance with WHO's *Putting women first* guidelines that emphasize women's safety, our resolution of ethical tensions between research design and dissemination prioritized this latter mandate above all.

## Conclusions

Our experience researching and disseminating research findings related to GBV and mental health in conflict-affected communities revealed that the prominence of various ethical principles shifted dynamically. Depending on the stage of research, some principles became more central than others, requiring accordingly responsive procedures and protocols. The fluctuating nature and significance of ethical principles produced identifiable tensions when it came time to disseminate findings. One particular tension arose between collecting data using safe and unharmed methods and distributing research findings equitably. Another ethical issue concerned transparently sharing findings of problems in a hopeful and contextualized way that would facilitate community action to address problems. Recommended dissemination strategies are to plan for dissemination a priori, engage with partners at local levels, and ground dissemination for action in evidence-based practices.

## References

1. C. Garcia-Moreno, H. Jansen, M. Ellsberg, et al., "Prevalence of intimate partner violence: findings from the WHO multi-country study on women's health and domestic violence," *The Lancet* 368 (2006), pp. 1260-1269.
2. United Nations. *Declaration on the Elimination of Violence against Women* (1993).
3. M. Ellsberg, H. A. F. M. Jansen, L. Heise, et al., "Intimate partner violence and women's physical and mental health in the WHO multi-country study on women's health and domestic violence: an observational study," *The Lancet* 371/9619 (2008), pp. 1165-1172.
4. Human Security Research Group, *Human Security Report 2013: The Decline in Global Violence: Evidence, Explanation, and Contestation* (2014).
5. United Nations Population Fund, Gender-based violence in humanitarian settings, 20 Available at <https://www.unfpa.org/resources/gender-based-violence-humanitarian-settings>.
6. United Nations, *Conflict-related sexual violence* (2017).
7. World Health Organization, *Violence against women* (2016).
8. L. Stark and A. Ager, "A systematic review of prevalence studies of gender-based violence in complex emergencies," *Trauma Violence Abuse* 12/3 (2011), pp. 127-134.
9. American Psychological Association, *Ethical Principles of Psychologists and Code of Conduct*, 20 Available at <https://www.apa.org/ethics/code/>.
10. E. J. Emanuel, D. Wendler, and C. Grady, "What Makes Clinical Research Ethical," *JAMA*, 283/20, (2000), pp 2701-2711.
11. L. A. Fontes, "Ethics in violence against women research: the sensitive, the dangerous, and the overlooked," *Ethics & Behavior* 14/2 (2004), pp. 141-174; A. K. Blanchard, C. A. T. M. Sangha, S. G. Nair, et al., "Pursuing authenticity from process to outcome in a community-based participatory research study of intimate partner violence and HIV Vulnerability in North Karnataka, India," *Qualitative Health Research* 27/2 (2017), pp. 204-214.
12. A. Aldous, M. Magnus, A. Roberts, et al., "Challenges in conducting research on sexual violence and HIV and approaches to overcome them," *American Journal of Reproductive Immunology (New York, N.Y.: 1989)* 78/1 (2017).
13. K. Shannon, V. Bright, S. Allinott, et al., "Community-based HIV prevention research among substance-using women in survival sex work: the Maka Project Partnership," *Harm Reduction Journal* 4 (2007), p. 20.
14. R. Jewkes, C. Watts, N. Abrahams, et al., "Ethical and methodological issues in conducting research on gender-based violence in Southern Africa," *Reproductive Health Matters* 8 (2000), pp. 93-103.
15. World Health Organization, *Putting women first: Ethical and safety recommendations for research on domestic violence against women* (2001).
16. A. Norris, A. Jackson, and K. Khoshnood, "Exploring the ethics of observational research: The case of an HIV study in Tanzania," *AJOB Primary Research* 3/4 (2012), pp. 30-39.
17. R. Zlotnik Shaul, L. Reid, B. Essue, et al., "Dissemination to research subjects: operationalizing investigator accountability," *Accountability in Research* 12/1 (2005), pp. 1-16.
18. B. Dauda and K. Dierickx, "Benefit sharing: an exploration on the contextual discourse of a changing concept," *BMC Medical Ethics* 14 (2013), p. 36.
19. J. H. Solbakk, "In the ruins of Babel: pitfalls on the way toward a universal language for research ethics and benefit

sharing,” *Cambridge Quarterly of Healthcare Ethics: CQ: The International Journal of Healthcare Ethics Committees* 20/3 (2011), pp. 341–355.

20. R. S. Purvis, T. H. Abraham, C. R. Long, et al., “Qualitative study of participants’ perceptions and preferences regarding research dissemination,” *AJOB Empirical Bioethics* 8/2 (2017), pp. 69–74.

21. Council for International Organizations of Medical Sciences (CIOMS), *International Ethical Guidelines for Biomedical Research Involving Human Subjects*.

22. World Health Organization, “Ethical and safety recommendations for intervention research on violence against women,” *Putting Women First: Ethical and Safety Recommendations for Research on Domestic Violence against Women* (2016), pp. 1–40.

23. P. G. Chen, N. Diaz, G. Lucas, et al., “Dissemination of results in community-based participatory research,” *Am J Prev Med* 39/4 (2010), pp. 372–378.

24. C. R. Horowitz, M. Robinson, and S. Seifer, “Community-based participatory research from the margin to the mainstream: are researchers prepared?,” *Circulation* 119/19 (2009), pp. 2633–2642.

25. I. Rivkin, J. Trimble, E. D. S. Lopez, et al., “Disseminating research in rural Yup’ik communities: challenges and ethical considerations in moving from discovery to intervention development,” *International Journal of Circumpolar Health* 72 (2013).

26. M. S. Goodman, S. Thompson, and V. L., “The science of stakeholder engagement in research: classification, implementation, and evaluation,” *Translational Behavioral Medicine* 7/3 (2017), pp. 486–491.

27. J. Kaye, “The tension between data sharing and the protection of privacy in genomics research,” *Annual Review of Genomics and Human Genetics* 13 (2012), pp. 415–431.

28. A.-M. Turcotte-Tremblay, and E. Mc Sween-Cadieux, “A reflection on the challenge of protecting confidentiality of participants while disseminating research results locally,” *BMC Medical Ethics* 19/Suppl 1 (2018), p. 45.

29. A. Baylor, C. Muzoora, M. Bwana, et al., “Dissemination of research findings to research participants living with HIV in rural Uganda: challenges and rewards,” *PLoS Medicine* 10/3 (2013), p. e1001397.

30. Internal Displacement Monitoring Center & Norwegian Refugee Council, Uganda: Difficulties continue for returnees and remaining IDPs as development phase begins, 20 Available at <http://www.internal-displacement.org/countries/uganda>.

31. J. J. Mootz, S. D. Stabb, and D. Mollen, “Gender-based violence and armed conflict: A community-informed socio-ecological conceptual model from Northeastern Uganda,” *Psychology of Women Quarterly* 41/3 (2017).

32. J. J. Mootz, F. K. Muhanguzi, P. Panko, et al., “Armed conflict, alcohol misuse, decision-making, and intimate partner violence among women in Northeastern Uganda:

a population level study,” *Conflict and Health* 12 (2018), pp. 1–11.

33. WHO - World Health Organization, “Putting Women First: Ethical and Safety Recommendations for Research on Domestic Violence Against Women,” *World Health Organization* (2001), p. 33.

34. B. A. Israel, A. Schulz, E. Parker, et al., “Critical issues in developing and following CBPR principles,” in M. Minkler and N. Wallerstein (eds), *Community-based particip. res. heal. from process to outcomes* (Jossey-Bass, 2008), pp. 47–66.

35. M. Y. H. Brave Heart, “The historical trauma response among natives and its relationship with substance abuse: A Lakota illustration,” *Journal of Psychoactive Drugs* 35/1 (2003), pp. 7–13.

36. B. McDavitt, L. M. Bogart, M. G. Mutchler, et al., “Dissemination as dialogue: building trust and sharing research findings through community engagement,” *Preventing Chronic Disease* 13 (2016), p. 150473.

37. M. Weissman, J. Markowitz, and G. Klerman, *The guide to interpersonal psychotherapy: Updated and expanded version* (Oxford University Press, 2018).

38. S. D. Ritchie, M. J. Wabano, J. Beardy, et al., “Community-based participatory research with Indigenous communities: The proximity paradox,” (2013).

39. Central Intelligence Agency, *The World Factbook: Africa*, 20

40. J. Strang, J. McCambridge, S. Platts, et al., “Engaging the reluctant GP in care of the opiate misuser Pilot study of change-orientated reflective listening (CORL),” *Family Practice* 21/2 (2004).

# Documenting the Impact of Conflict on Women Living in Internally Displaced Persons Camps in Sri Lanka: Some Ethical Considerations

SHANA SWISS, PEGGY J. JENNINGS, K. G. K. WEERARATHNE, AND LORI HEISE

## Abstract

Women's Rights International works with rural women and girls who are living in countries at war or with ongoing political violence. In 2005, The Asia Foundation invited Women's Rights International to Sri Lanka to evaluate the feasibility of a random-sample survey of women to document the impact of the decades-long conflict. The significant imbalance in the risks-to-benefits ratio compelled us to recommend that random-sample surveys that included questions about sexual violence be avoided at that time, especially in the displaced persons areas. Instead, we recommended that three strategies be given priority in situations in which the risks for women are too great to justify a random-sample survey. First, maximize the use of existing information. Second, collect survey data only in partnership with a strong community organization that will use the data for direct tangible benefits. Third, share knowledge that will help build the capacity of local organizations to design surveys that address their priorities, and collect and use their own data following ethical guidelines that maximize the protection of individuals and the wider community. We implemented these recommendations in a partnership with a local organization with a strong history of advocating for women's rights.

---

SHANA SWISS, MD, is founder and director of Women's Rights International, San Francisco, USA, and project director with People's Palace Projects, Queen Mary University of London, UK.

PEGGY J. JENNINGS, PhD, is an independent data analyst and consultant and a former research and education specialist at Women's Rights International, San Francisco, USA.

K. G. K. WEERARATHNE is secretary of the Vehilihini Development Centre, Monaragala, Sri Lanka.

LORI HEISE, PhD, is a professor of gender, violence, and health at the Johns Hopkins Bloomberg School of Public Health and the Johns Hopkins University School of Nursing, Baltimore, USA.

Please address correspondence to Shana Swiss. Email: [wri@womens-rights.org](mailto:wri@womens-rights.org).

Competing interests: None declared.

Copyright © 2019 Swiss, Jennings, Weerathne, and Heise. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original authors and source are credited.

## Introduction

Women's Rights International (WRI) works with local organizations in countries in conflict to adapt research methods and participatory approaches to document the impact of conflict on women and girls, and to support efforts by community groups to develop creative programs that address the effects of war and violence on women's lives. We have taken innovative programs to regional and national scales using existing networks, such as training programs for traditional birth attendants through the Ministry of Health in Liberia, and low-power FM radio stations formed by community groups throughout Haiti. Ethical and safety considerations are at the forefront of WRI's work with communities. Data collection efforts must be conducted in partnership with an existing organization, serving the interests of that organization, driven by community needs and interests, and carried out by women who belong to the population or community from which the data are collected. We have developed tools, such as data security and monitoring plans, for promoting ethical relationships between local, national, and international organizations that collect or have access to human rights data and other sensitive information. Our principles for working respectfully with the priorities and knowledge of local groups and with deep community participation have been influenced by ethical guidelines developed by indigenous peoples and by others who share our priorities of ethical partnerships between individuals and organizations in which there may be an imbalance of knowledge or power in a given context.<sup>1</sup>

Over the past 25 years, WRI has worked with women and local organizations during active conflict or political violence in the former Yugoslavia, Liberia, Haiti, and Sri Lanka. Each of those data collection efforts presented unique risks, pressures, and ethical challenges. When the editors of this special issue invited us to submit an article about the ethical challenges we have faced while working in conflict settings, we chose to describe a project we carried out in Sri Lanka during 2005–2006. This article describes how ethical decision making in the field played a significant role in determining the nature of the field work in an ongoing conflict

situation in which the conditions for protecting participants and researchers were complex, dynamic, and rapidly changing. We describe here the all-too-common situation in which the pressures for collecting human rights data can be in apparent contradiction with ethical obligations to protect individuals at risk who may be asked to provide those data. We are well aware that the pressures on academic researchers and human rights advocates can make it difficult or impossible to make an ethical decision to discontinue a fieldwork project once it has been set in motion. For that reason, we present some alternative methodological strategies for adjusting fieldwork objectives and methods in order to accommodate the mutual imperatives of using data to support human rights advocacy while at the same time protecting the safety and confidentiality of individuals living under dangerous conditions.

In 2005, The Asia Foundation invited WRI to Sri Lanka to evaluate the feasibility of conducting a random-sample survey of the impact on women of the decades-long civil conflict. The survey was intended to complement ongoing efforts by the Human Rights Accountability Coalition (HRAC), a group of Sri Lankan human rights organizations, to document political and ethnic violence. The HRAC members were concerned that human rights violations against women were not well captured in their documentation efforts using a variety of sources, such as victim and witness statements, legal case files, and newspaper reports, among others.<sup>2</sup> Their objective in consulting with WRI was to enhance their data collection efforts by using statistical sampling methods to interview women selected at random to get a more accurate estimate of the scope of human rights violations, including sexual violence. (Note: This article discusses fieldwork carried out during 2005 and 2006, prior to the military campaigns that began in late 2006 and the displaced persons camps set up in 2009. These subsequent events have received severe criticism both by the United Nations and other human rights organizations for serious human right violations. Those events are not reflected in the fieldwork discussed here.<sup>3</sup>)



## Methods

This section describes the methods we used in the field to evaluate safety and to make decisions about adjusting the data collection effort to balance the objectives of supporting advocacy for women's human rights while protecting the safety of those women who might be asked to provide this sensitive information.

Our initial assessment addressed some of the ethical preconditions for research involving internally displaced people (IDP).<sup>4</sup> First, we verified that although there were a few existing reports addressing the impact of the conflict on women, none had been able to obtain an accurate estimate of the scope of human rights violations against women, particularly sexual violence, during the conflict.<sup>5</sup> Second, we confirmed that there were a number of established and well-respected local and international humanitarian aid, development, and health care nongovernmental organizations (NGOs) working in the conflict-affected regions that were well positioned to be potential partners in a survey effort and would likely be able to use the results to provide direct benefits to participants.

We next considered the safety and ethical issues that would be involved in carrying out a survey of women living in the IDP areas. Three fundamental principles based on ethical standards for biomedical research served, among others, as our guidelines: (1) respect for the autonomy of individuals, (2) the obligation to provide beneficial outcomes commensurate with risk; and (3) the imperative to distribute the receipt of benefits and the burden of risk fairly and justly.<sup>6</sup> We traveled to some of the conflict-affected regions of the country and consulted with local NGOs (including those serving women and those serving internally displaced people), experts, community members, women's rights activists, lawyers, physicians, legal aid organizations, women's empowerment groups, and women and girls living in displaced persons camps and IDP areas. Most of these meetings took place in Colombo, Vavuniya, and Batticaloa. At the time of our assessment, portions of the northern and eastern regions were inaccessible because the conflict was still ongoing at that time.

## Findings

It was through this more extensive local assessment of safety, ethical, and data-quality issues that it became evident that the environment in Sri Lanka for women's fundamental rights was so difficult, particularly in the IDP areas, that it was neither safe, ethical, nor feasible to select women at random and encourage them to disclose experiences of sexual violence. Three main areas of risk embedded in the social and legal context for women led to our conclusion that random-sample survey research that included questions about sexual violence could be ethically carried out only under very limited conditions.

### *Risks related to social and legal conditions*

The first and primary risk factor was the significant social consequences of "shame," or losing face. If a woman revealed that she had been raped or sexually abused, she faced the very real risk of being ostracized from her family, her community, and Sri Lankan society in general. She may never be able to marry or, if she was already married, she may be rejected and abandoned by her husband and in-laws. She may face violent retribution from the perpetrator as severe as maiming from acid burns or even murder. She may commit suicide. Further, she may be placed involuntarily in indefinite state detention under "protective" custody. Second, the nature of the law enforcement and justice system was such that a woman who came forward with a complaint or charge of sexual abuse could not rely on adequate protection or redress. Women faced significant obstacles to receiving adequate treatment at every step in the process, from lodging a complaint with the police, to receiving appropriate service from lawyers, prosecutors, judges, and the prison system, to seeing the case brought to court in anything less than six to ten years or more. Sri Lankan laws themselves were such that a woman was at a disadvantage in nearly every legal situation, whether it was land rights, "vagrancy," domestic violence, or sexual assault.

### *Risks related to displacement*

Women in the IDP areas were living under con-

ditions that compounded the curtailment of their fundamental rights and put them at additional risk of harm from a random-sample survey on human rights violations. In addition to the social and legal background conditions, women living in the IDP camps were extremely vulnerable to exploitation because they were dependent on the state, with little ability to determine the course of their own lives. A large majority of them had been displaced for 10 years or more under conditions in which basic dignity and fundamental rights were merely ideals. Their ability to freely make decisions about their own best interests had been curtailed nearly completely. They had no access to land, had few options for income generation, and had only within the last few years been able to move freely in and out of the camps without requiring authorization from camp officials. Neighbors lived side by side in 10-by-10-foot rooms, separated only by plywood or fiberboard. Privacy was difficult to obtain even for toileting and bathing, let alone for a confidential interview. At any moment, depending on the decree of government military or police officials, people in camps would find themselves living essentially in detention, under imposed curfew, or under a number of other limits on their basic freedoms.

### *Risks related to data quality*

In Sri Lanka in 2005, partly as a result of the decades-long conflict in the northern and eastern regions, and the devastating tsunami that affected much of the coastline in 2004, there had been a prolonged presence of international, national, and local NGOs providing assistance and interventions. Most, if not all, of those NGOs collected information in order to carry out their mandates. Because some of these NGOs did not communicate effectively with one another or share information, people living in the IDP areas were asked to provide the same information, including details about human rights violations, to multiple organizations for multiple purposes. During our discussions with NGO staff who worked in the displaced persons camps, we heard that people living in the camps had grown skeptical and resentful about participating in interviews and surveys because they had

revealed their experiences of abuse many times and their expectations of benefit were not realized. Further, short of persuading each woman to disclose the details of the abuses she had suffered over the more than 20 years of conflict and displacement (details she may have chosen to keep hidden for her own sake), there was, at that time, not much that had not already been documented about the situation of women living in the camps. Although the findings from many of the previous surveys tended to be kept within the organization that collected the data, some very good studies had been published that clearly laid out the issues facing women living in the IDP areas in Sri Lanka.<sup>7</sup> Yet the dire situation for women in the camps remained.

### Conclusions

The significant imbalance in the ratio of risks and benefits compelled us to recommend that new efforts to conduct random-sample surveys that included questions about sexual violence be avoided at that time, especially in the IDP areas. Choosing a woman at random and encouraging her to disclose information about rape or other sexual abuse, or other topics that may cause her or her family to lose face, would have been asking her to take on a very high level of risk.

Further, we concluded that it would be unethical to expect that a woman living under these extreme hardships in the IDP camps could freely and autonomously, without the presence of coercion or misperception, weigh the risks and benefits of disclosing sexual violence in a survey that she may have perceived as being linked to aid.<sup>8</sup> Unless an NGO planning to conduct a survey that included questions about sexual violence could provide immediate useful benefits to participants, the risk-to-benefit ratio of conducting such a survey was unacceptably high.

We also believed it was unlikely that a survey would yield accurate data on sensitive topics in which a woman may have feared the consequences of disclosing sexual violence. Because the risks were so high, many women in the sample population may have chosen not to disclose sensitive

information, and the survey results would have been inaccurate and potentially harmfully misleading. Furthermore, if the resulting survey data were inaccurate, and useless for advocating for services or justice, the women who *had* chosen to disclose information would have taken risks (and potentially endured harm) for no benefit whatsoever. It was our view that it would have been unethical to put any Sri Lankan woman at additional risk when the findings would have been of limited use at best—and more likely harmful.

In settings where the emergency situation is repeated or prolonged, data can take on a particular value that makes organizations reluctant to share it. When funding for programs is limited, NGOs may be compelled to compete with one another in order to have exclusive information that supports a unique proposal for new or continued funding. Such an environment creates additional risks for the vulnerable individuals who provide information. It was also not uncommon at the time for outside organizations who had partnered with local NGOs to collect data, then retain ownership of those raw data and findings without bringing back the findings or specifying the local NGO's rights to those data. When outside organizations extract data through a partnership with a local NGO, they impede the local NGO's ability to use its own judgment to decide when and how to share the data or report the findings in ways that maximize local benefits and protect the community of individuals who provided the data.

The consequences for publicly disclosing sexual violence were very serious for Sri Lankan women, and, as a result, women generally did not disclose the sexual violence in their lives, except under extreme or unusual situations.<sup>9</sup> Some Sri Lankan women did, however, choose to come forward and disclose sexual violence in order to seek justice or medical treatment. We believe that from an ethical standpoint, a woman who chooses to face these risks does so because she perceives that the significant and direct potential benefits of seeing the perpetrator brought to justice or receiving necessary medical or psychosocial services warrant the risks. A random-sample survey, however, would have solicited information about

sexual violence from women who had not previously volunteered it.

Despite the risks, and because of the risks, there remains an urgent and pressing need to document the scope of all types of violence against women during conflict. Accurate and systematic documentation is needed to dispel a strictly enforced culture of silence and acceptance of violence against women. But until we can find a way to break that silence without requiring women to endure the substantial risks of coming forward before it is safe to do so, the problem of sexual violence against women will continue to be denied and ignored.

## Recommendations

We recommend three general strategies that should be given priority in situations in which the risks for women are too great to justify a random-sample survey: (1) maximize the use of existing information; (2) collect survey data *only* in partnership with a strong community-based NGO that will use the data for direct tangible benefits; and (3) help build the capacity of local NGOs and NGO coalitions to collect and use data following ethical guidelines that are appropriate for their communities and that maximize the protection of individuals.

### *Maximize the use of existing information*

We must maximize the use of the existing data from women who choose independently to bear the risks of disclosure. In addition, we must be creative in identifying and using existing data that were not originally collected for human rights purposes. For example, one of the authors and her colleagues used hospital records about women who became pregnant as a result of rape to obtain an estimate of the number of women raped in the former Yugoslavia during that conflict.<sup>10</sup> In our view, the potential for using existing data to shed light on the scope of sexual violence in conflict is an avenue that deserves significant exploration.<sup>11</sup>

All possibilities for using quantitative methods on existing legal, medical, and social service records to unveil the scope and reality of violence in women's lives should be explored and fully con-

sidered. Analyses of existing records could in some cases be done by supporting local organizations and institutions in using their existing documents in a safe and ethical manner to generate de-identified data to share with other organizations. Facilitating the open sharing of de-identified data among NGOs must be done only in a context where the protection of individual identities can be appropriately accomplished. Sharing data will reduce the risks associated with face-to-face interviews, but it may increase the risk of breach of confidentiality. We recommend that NGOs that share data formulate and adopt a data security and monitoring plan, a set of agreed-on principles and specific practices under which data will be shared without compromising the safety of the individuals who provided it.<sup>12</sup>

#### *Partner with a strong local organization*

If a survey is conducted, it must be done with a well-established, well-respected local organization working with women in that community, and it must be done within the framework of their programmatic objectives. In Sri Lanka, there were a number of community-based NGOs that had built up substantial credibility over long years of service and advocacy. We must share knowledge with these strong local organizations that supports their efforts to collect their own data within ethical guidelines to meet their own needs.

#### *Support the protective capacities of local organizations and coalitions*

We recommend sharing knowledge that builds the capacity of local NGOs to conduct *local* ethical review of data collection efforts, to protect confidentiality, and to enhance the security of electronic files and paper documents where the safety of individuals is a concern. It is the fieldworker's responsibility to ensure appropriate ethical review of any data collection effort in which he or she is involved. An appropriate review must reflect sufficient expertise on the local conditions.<sup>13</sup> In addition, the fieldworker should always appoint a group of individuals from the regional or national level to serve as a safety and monitoring committee to consider questions related to safety and ethics.<sup>14</sup>

## Epilogue: Fieldwork in support of human rights

The Asia Foundation respected our recommendation not to go forward with a random-sample survey of women's human rights violations in the IDP areas as long as the conditions remained unsafe for women to disclose sensitive information. The original intent behind conducting a survey on women's human rights, however, was to support The Asia Foundation's programs advocating for women whose lives had been affected by the political and ethnic violence in Sri Lanka. But rather than give up on the goal of documenting human rights violations against women, foundation staff asked us to help them implement our recommendations in a partnership with a local NGO with a strong history of advocating for women whose lives had been affected by human rights abuses during an earlier period of political violence.

In 2006, we partnered with the Vehilihini Development Centre (VDC), a local NGO in Monaragala, the epicenter of a period of political violence in which 30,000–60,000 men were “disappeared” in the late 1980s. VDC had been working on behalf of the widows of the disappeared for nearly 20 years, helping them challenge some of the social and legal issues that were limiting women's fundamental rights. In the 1990s, VDC staff surveyed widows of the disappeared men to document the devastating impact that the political violence and discriminatory customs had on these women's lives, including losing their access to housing and land after becoming widows. Using the results of their survey, VDC initiated and sustained a six-year campaign that helped achieve significant reform of the country's land inheritance laws. In 2006, VDC and our local advisors felt that it was the right moment in history to be able to ask these widows about more sensitive issues related to the earlier political violence, particularly now that the impacts could be traced through three generations. A new survey of the widows of the disappeared men could reveal important information about conflict-related issues still affecting women in that region. By focusing on disappearances, a single phenomenon related to conflict, and by exploring the longer-term impacts

on women and their families, the new survey could reveal a cross-section of issues that, if left unresolved, could presumably be affecting Sri Lankan women and their families in the current conflict.

Through our partnership with VDC, we worked closely together to conceptualize the survey questions that would be most effective in quantifying the issues that VDC wanted to address. VDC staff shared their knowledge about the complex social, cultural, and legal issues that were affecting the widows in their district of Monaragala. We shared our knowledge about research ethics, survey design, and data collection while VDC staff created and conducted their own survey, collected the data, created a database, entered the data into EpiInfo, generated their own results, created reports on their findings, and used them to advocate for services for families of the disappeared.<sup>15</sup> We facilitated a process of ethical decision making about how to conduct the survey in a way that would minimize risk to the women and maximize VDC's ability to provide tangible benefits. We collaborated on the development of a research and safety advisory committee, as well as a data safety and monitoring plan that assured the organization's ownership rights over the survey data and its rights to use its own judgment about how to use and share the data in accordance with ethical safety guidelines that protected the women who provided the information.<sup>16</sup> Our working relationship with VDC embodied as much as possible the principles of community-based participatory research that are also codified in indigenous-based guidelines for ethics review.<sup>17</sup> At the time of publication, VDC was still working successfully in Monaragala on behalf of women's rights.

### *Closing summary*

No conflict starts with the first bullet fired, nor does it end with the last. When the pressures of collecting data in a dangerous situation are in apparent contradiction with the imperative to protect participants, two of the most valuable tools a fieldworker can use are a broad perspective and a long view. In some situations, safely collecting data about past related events may serve the overall objectives as

well as, or better than, collecting risky data about current events. Before we approach individual women selected at random and ask them to endure risks, we must leverage existing data to challenge and repair the system that keeps women silent, and we must respect their willingness to endure risks by providing tangible benefits as quickly as possible. We must also take a long-term view in helping local organizations obtain the technical knowledge they need to collect and share information in ways that protect women's safety and allow women to advocate more powerfully on their own behalf.<sup>18</sup>

Admittedly, some things have changed since 2005 that might affect the calculus of conducting such studies today. Innovations such as audio computer-assisted interviewing now allow even non-literate women to listen and respond in total privacy to recorded questions using headphones and tablets. This could help avoid some of the stigma and safety concerns we grappled with; however, it raises many other concerns, such as the psychological impact, still unexplored, of asking women about past trauma and abuse via the isolating modality of headphones. For women unaccustomed to hearing intimate questions asked by recording, this approach could be experienced as even more invasive and triggering than questions asked out loud by an empathetic interviewer.

The political and donor environments around researching violence in conflict have also changed, in good ways and bad. Far more attention is now given to these issues, as evidenced by United Nations Security Council Resolution 1325 and high-level events such as the UK-sponsored Global Summit to End Sexual Violence in Conflict. While the increased attention is welcome at one level, advocates and researchers have criticized the singular focus on *sexual* violence by combatants, noting that even in conflict and post-conflict settings, research has demonstrated that violence by partners and other non-combatants is the dominant form of violence that women face. Research has helped widen the focus of this lens, and the global policy community must follow.

With the rise of evidence-based policy and increasing pressure on donors and grantees to



demonstrate “results,” there are fewer donors willing to support the type of thoughtful evaluation of risk and benefit that we were allowed to pursue in Sri Lanka. The pressures for quick assessment, quantitative data to guide programming, and evidence of “impact” are far greater today than they were in 2005. These forces only increase the potential that we will impose greater risks in our haste to help.

So, while some things have changed, many challenges remain. In our view, we should ask women to participate in random-sample survey research on sexual and domestic violence in conflict settings only when we are confident that the benefits outweigh the risks, other sources of data are not available, and every effort has been made to minimize harms and ensure the data will be used by local partners to benefit women.

## Acknowledgments

We are grateful to the late Herbert F. Spierer for his vision, passion, and pioneering accomplishments in the quantitative documentation of human rights. All of our work has been informed and inspired by Herb. The human rights community misses him dearly, as do we. But we will carry on as he taught us to do—counting as carefully, creatively, and ethically as we can.

## References

1. Navajo Nation Health Research Review Board, *Procedural guidelines for principal investigators*. Available at <http://www.nnhrb.navajo-nsn.gov/pdf/Procedural%20Guidelines%20for%20PI.pdf>; Canadian Institutes of Health Research, *Tri-council policy statement: Ethical conduct for research involving humans* (Ottawa: Canadian Institutes of Health Research, 2014); TRUST, *Global code of conduct for research in resource-poor settings* (2018). Available at [http://ec.europa.eu/research/participants/data/ref/h2o2o/other/hi/coc\\_research-resource-poor-settings\\_en.pdf](http://ec.europa.eu/research/participants/data/ref/h2o2o/other/hi/coc_research-resource-poor-settings_en.pdf); J. Goodhand, “Research in conflict zones: Ethics and accountability,” *Forced Migration Review* 8 (2000), pp. 12–15; J. Leaning, “Ethics of research in refugee populations,” *Lancet* 357 (2001), pp. 1432–1433; E. J. Emanuel, D. Wendler, J. Killen, et al., “What makes clinical research in developing countries ethical? The benchmarks of ethical research,” *Journal of Infectious Diseases* 189/5 (2004), pp. 930–937.
2. Organisation for Economic Co-operation and Development, “Massive human rights violations in Sri Lanka,” *OECD Journal on Development* 9/2 (2008), pp. 133–145.
3. See, for example, United Nations Human Rights Council, Report of the OHCHR Investigation on Sri Lanka, UN Doc A/HRC/30/CRP.2 (2015); Human Rights Watch, *Country summary: Sri Lanka* (January 2010).
4. Leaning (see note 1).
5. Amnesty International, *Amnesty International report 2005: Sri Lanka* (2005). Available at <https://www.refworld.org/docid/429b27eb11.html>; Human Rights Watch, *Human Rights Watch world report 2005: Sri Lanka* (2005). Available at <https://www.refworld.org/docid/421da31a28.html>.
6. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *The Belmont report: Ethical principles and guidelines for the protection of human subjects of research* (Bethesda, MD: National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979).
7. S. Elek, *Choosing rice over risk: Rights, resettlement, and displaced women* (Colombo: Centre for the Study of Human Rights, University of Colombo, 2003).
8. See, for example, C. Siriwardhana, A. Adikari, K. Jayaweera, and A. Sumathipala, “Ethical challenges in mental health research among internally displaced people: Ethical theory and research implementation,” *BioMed Central Medical Ethics* 14 (2013), pp. 13–20.
9. See, for example, K. de Jong, M. Mulhern, N. Ford, et al., “Psychological trauma of the civil war in Sri Lanka,” *Lancet* 359 (2002), pp. 1517–1518.
10. S. Swiss and J. E. Giller, “Rape as a crime of war: A medical perspective,” *Journal of the American Medical Association* 270 (1993), pp. 612–615.
11. F. Roth, T. Guberek, and A. H. Green, *Using quantitative data to assess conflict-related sexual violence in Colombia: Challenges and opportunities* (Colombia: Corporación Punto de Vista, 2011).
12. Women’s Rights International, *Data security and monitoring plan: Steps for protecting the safety of participants and the security of data* (2006). Available at <http://womens-rights.org/Documenting/DSMP.html>; P. Rodríguez Espinosa and A. Richmond, “Appendix 9. Partnership agreements: A practical guide to developing data sharing, ownership, and publishing agreements,” in N. Wallerstein, B. Duran, J. Oetzel, and M. Minkler (eds), *Community-based participatory research for health: Advancing social and health equity* (San Francisco, CA: Jossey-Bass, 2017), pp. 385–391.
13. D. Schopper, A. Dawson, R. Upshar, et al., “Innovations in research ethics governance in humanitarian settings,” *BioMed Central Medical Ethics* 16 (2015), pp. 10–21; S. Mezińska, P. Kakuk, G. Mijaljica, et al., “Research in disaster settings: A systematic qualitative review of ethical guidelines,” *BioMed Central Medical Ethics* 17 (2016), pp. 62–72; K. Ahmad, “Developing countries need effective ethics

review committees,” *Lancet* 362 (2003), p. 627; A. Sumathipala and S. Siribaddana, “Research and clinical ethics after the tsunami: Sri Lanka,” *Lancet* 366 (2005), pp. 1418–1420.

14. See, for example, C. J. Kovats-Bernat, “Negotiating dangerous fields: Pragmatic strategies for fieldwork amid violence and terror,” *American Anthropologist* 104/1 (2002), pp. 1–15.

15. Centers for Disease Control, *Epi info* (software). Available at <https://www.cdc.gov/epiinfo/index.html>.

16. Women’s Rights International (see note 12).

17. See, for example, Navajo Nation Health Research Review Board (see note 1).

18. See, for example, J. V. Lavery, S. V. S. Bandewar, J. Kimani, et al., “‘Relief of oppression’: An organizing principle for researchers’ obligations to participants in observational studies in the developing world,” *BioMed Central Public Health* 10 (2010), pp. 384–390.



# Witnessing Obstetric Violence during Fieldwork: Notes from Latin America

ARACHU CASTRO

## Abstract

Violence against women in labor occurs frequently in Latin America, based on observations from my extensive ethnographic fieldwork in various Latin American countries. In this article, focused on Mexico and the Dominican Republic, I contextualize obstetric violence within the larger context of social exclusion and discrimination against women. I establish associations between maternal deaths and health care systems characterized by a lack of continuum of care, a lack of accountability toward women, and the withholding of care. I argue that clinical staff learn to operate within the structural limitations of health care systems by not assuming the responsibility of the continuum of care that each woman needs, and that this discharge of accountability is at the heart of how health professionals can navigate, tolerate, and perpetuate the structure of the system and, in so doing, create the breeding ground for obstetric violence to occur. Finally, I explain that although reporting on the suffering of women will not, on its own, prevent obstetric violence, increasing its visibility through research can contribute to human rights-based advocacy on behalf of women in labor, to the monitoring of human rights standards, and to the creation of accountability measures within health systems to prevent obstetric violence.

---

ARACHU CASTRO, PhD, MPH, is Samuel Z. Stone Chair of Public Health in Latin America in the Department of Global Community Health and Behavioral Sciences at the Tulane University School of Public Health and Tropical Medicine, New Orleans, USA, and President of the Society for Medical Anthropology.

Please address correspondence to the author. Email: [acastro1@tulane.edu](mailto:acastro1@tulane.edu).

Competing interests: None declared.

Copyright © 2019 Castro. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

## Witnessing violence against women in labor

I have conducted fieldwork in public hospitals across Latin America since 1998. In every case, the administrators of public hospitals and health centers allowed me in as part of research projects conducted collaboratively between my United States-based university—Harvard University until 2012 and Tulane University since 2013—and ministries of public health, at times also involving international organizations. These studies, conducted in Mexico, Cuba, Colombia, Peru, Nicaragua, and the Dominican Republic, received ethical review approval. Their methodologies included open-ended interviews with women and health professionals, the observation of clinical encounters in public health facilities during pregnancy and childbirth, and epidemiological data analysis.<sup>1</sup> I served as research director for these studies and, as an academic trained both in medical anthropology and in public health, I had both the urge and the curiosity to observe women's experiences in a clinical setting, without intermediaries. Having given birth twice before I started research related to childbirth allowed me, at least to a certain extent, to understand other women's experiences from a vantage point of shared human experience. My preliminary concerns around seeing blood easily subsided, but my struggle as an observer of violence against women and of human rights violations became a real predicament.

The first time I observed a woman giving birth, I was researching the rise of cesarean sections in Mexico. The 20-year-old woman in labor had no obstetric complications, but she had to endure several threats from her female obstetrician, who kept yelling at her because she refused epidural anesthesia as a result of how painful it had been during her previous childbirth. Her plea to not be punctured was unsuccessful, and she gave birth to a healthy child a few minutes later. While the doctor took the newborn to a side table to conduct the Apgar test, the young woman kept asking if her child was a boy or a girl. Given that nobody was answering and that I was standing between the woman and the child, I told her she had a boy. Later that week, I observed my first birth by cesarean section:

*July 14, 1998. In a large public maternity hospital in Mexico City, Antonia arrives in a wheelchair at the operating room. She is 23, mother of a young child, and is 37 weeks pregnant with twins, one of which is breeched. She is going to have a cesarean section, just like she had the first time she gave birth. Soon after the anesthetist places an epidural, most of her body starts to numb. A male surgeon arrives in the operating room and asks Antonia how many children she has. She responds one. The surgeon bluntly asks her if she's going to "get tied" this time—¿y te vas a ligar ya? Antonia says no, and the surgeon looks at her in dismay and leaves. Twelve minutes later the cesarean section begins. Two residents are performing the surgery, and there are a total of nine people around Antonia, including myself. The male surgeon comes back. Six minutes later, two healthy girls are born. While the residents are stitching Antonia, the male surgeon asks her: "Aren't you going to get tied?" Upon Antonia's firm and negative response, he gets mad at her and leaves.<sup>2</sup>*

I started to take these notes and to sketch a drawing of the operating room while seated on the floor against a wall, as I was concerned that I would not be able to withstand observing the surgery while standing up. Immediately after the procedure began, Antonia had asked if someone could hold her hand, but everyone around us seemed too busy to care about her request. I was compelled to get closer to her and hold her hand, and I did as soon as I realized I would be okay standing so close to the procedure without fainting. I was by her side while a medical doctor was yelling at her, trying to force her to agree to be permanently sterilized. I talked to her while memorizing the scene so that I could later record the episode in my notes.

Beyond some degree of empathy that I could transmit to these young women while they were giving birth, I knew that my presence during these critical moments in their lives was easily forgettable. In these and all the subsequent births that I observed, I did no harm, but did I do any good? As an anthropologist, I could at least see myself as a participant observer and not as a mere observer. I was interacting with the women in labor after all, but I was keeping quiet. At a minimum, I could write about it, and in doing so, I deliberately chose



the word violence to define these obstetric events:

*The increase of caesarean sections can thus be regarded as a process in which women are finally given less information and less choice and in which obstetricians appropriate the central role of childbirth at the expense of women. Finally, “violence” is a strong word, and labelling unnecessary caesarean sections as form of violence against women could be disturbing. But for many women, a caesarean section that could have been avoided is a violation of their bodily integrity, just like having routine episiotomy (or perineal cutting), epidural anesthesia without consent, non-indicated oxytocin induction or augmentation, multiple and painful vaginal examination, non-indicated amniotomy, or pubic shaving, needless exposure of sexual parts in common labour rooms, or even transcaesarean tubal ligations when women do not understand the permanent nature of the procedure. In order to give back to women the central role in childbirth, new guidelines aimed at restricting the use of caesarean sections and other birth technologies by improving the quality of care should be welcomed.<sup>3</sup>*

Scenes of violence against women in labor are the norm, rather than the exception, in the various Latin American countries where I have conducted ethnographic fieldwork. Beginning in 2009, I started to conduct fieldwork in hospitals in the Dominican Republic, first to explore the management of HIV and syphilis during pregnancy and then, having identified a series of issues that could be behind the country’s high maternal mortality ratio, to focus on referrals of women with obstetric complications and on the causes of their deaths.<sup>4</sup> In that context, I was in the labor room where a woman was giving birth vaginally, assisted by two residents, when the nurse, seated in the bench next to mine, told the woman in labor, *¡No grites tanto!* (Don’t scream that loud!). Not convinced that arguing with the nurse was the most effective way to bring that humiliation to an end, I decided to challenge her differently. If the nurse verbally attacked the woman in labor again, I would ask her why. “Excuse me, nurse, why did you tell her not to scream that loud? What is your purpose?” I struggled to navigate my appropriate role as a researcher in this context, wanting neither to compromise my access to the hospital nor to allow what I felt was

abusive behavior to go unchallenged. I felt this approach would potentially allow me to continue my research without being involved in an argument.

A few minutes later, I was invited to observe a cesarean section in a tiny operating room, wearing a white coat like during many other observations, and with the consent of the young woman in labor. Two obstetricians and an anesthesiologist were diligently caring for the woman. As in the past, and to prevent interfering with clinical care, I was standing against the wall, about three feet away from the woman in labor. A nurse kept passing between us. As the young woman’s abdomen was being cut, I purposely made eye contact with her and started a conversation. To my surprise, the nurse asked me, “What’s up, are you her relative or what?” I smiled, ironically, at the fact that showing some humanity could be considered out of place.

### Building a case for obstetric violence

In 2010, I started to collect data from medical records, verbal autopsies, and hospital case discussions of all reported maternal deaths in the capital city of Santo Domingo to determine the social context in which the deaths occurred and to establish which types of delays (in seeking medical care, in reaching the health facility, or in obtaining care once in the health facility) and which health system factors contributed to the deaths. The study was aimed at informing the national program to reduce maternal mortality. In 2008–2012, hypertensive disorders of pregnancy (mainly preeclampsia and eclampsia) constituted the first cause of the 625 reported maternal deaths in the Dominican Republic, accounting for 36% of cases, followed by hemorrhage, other obstetric complications, sepsis, and abortion; 55% of deaths occurred in Santo Domingo and the surrounding province.<sup>5</sup> But without understanding the social and health system contexts in which these happened, I argue that limiting the analysis to the ultimate cause of death would not be sufficient to create an efficient program to reduce maternal mortality.

Although the study was originally going to last 12 months, halfway into the research and hav-

ing studied the circumstances of 49 dead women, it became clear to me that, beyond the distribution of clinical causes, these women were dying according to set patterns. The patterns were systemic, produced mostly by the health care system. Health care systems vary in the way that they organize the functioning of teams, networks, and facilities; therefore, we can expect different health systems to achieve different epidemiological outcomes. With an average of one maternal death every four days in Santo Domingo and one death every other day in the country, these were not unpredictable or random, but expected events produced by the health system.<sup>6</sup>

The following three narratives present examples of maternal deaths that could have been prevented, according to the field epidemiologists who conducted the verbal autopsies of the three women and the maternal mortality review committees that discussed two of their deaths:

1. In August 2010, a 29-year-old domestic worker in the late stage of pregnancy and her husband went to the local rural public hospital where she had been receiving prenatal care. While waiting to be seen, she developed seizures, was treated with magnesium sulfate to prevent additional seizures, and was told to go to a larger hospital to continue her treatment. The woman and her husband took a two-hour bus ride on a bumpy road through sugarcane plantations to get to the closest general hospital—a ride that takes just 45 minutes by car. Upon their arrival at 12:40 p.m., she was diagnosed with severe preeclampsia, was treated with magnesium sulfate and hydralazine (a hypotensive medication), had an emergency cesarean section, and gave life to a newborn. Because her seizures were not subsiding and the intensive care unit was not operational, hospital staff immediately drove her by ambulance to the national maternity hospital in Santo Domingo, the capital city, where she arrived unconscious at 3:40 p.m. She was admitted and transferred to the intensive care unit, where she was treated for eclampsia. Five days later, due to neurological trauma, she was taken by ambulance with
2. In January 2011, a 27-year-old hotel janitor who was the mother of an eight-year-old was admitted to a nonprofit general hospital in Santo Domingo with vaginal hemorrhage, a high temperature, and jaundice—which had resulted from an unsafe curettage performed at a clandestine clinic two days earlier. Upon diagnosis of multiorgan failure, a multidisciplinary clinical team recommended an emergency blood transfusion and a laparotomy, followed by dialysis. The staff contacted her family, urging them to bring blood before they could perform any procedures. The following evening, after the family was able to find a suitable donor and bring blood to the hospital, the surgery began. The doctors discovered a massive internal hemorrhage and a punctured uterus, which they removed along with the woman's ovaries and fallopian tubes. One day later, after a multitude of severe symptoms, the woman died; her reported cause of death was septic abortion. A few days later, I accompanied the two epidemiologists who conducted the verbal autopsy at her family's home. The woman's parents and siblings explained that the hospital never informed them of the severity of the condition. Upon learning that she died as a result of "what cannot be spoken," her father said that "silence killed her." When epidemiologists from the health district tried to conduct

the maternal mortality review meeting at the hospital, the staff declined and directed the epidemiologists to identify the clandestine clinic, which they never found.

3. In February 2011, a 28-year-old woman in her 37th or 38th week of pregnancy and mother of four went to the emergency room of a public maternity hospital in Santo Domingo at 11:10 a.m. She was diagnosed with severe preeclampsia and was admitted to the prelabor room at 11:50 a.m. The staff contacted her family members by phone, urging them to bring blood. At 7 p.m., after the family brought the blood, the blood transfusion and cesarean section began under epidural anesthesia. The woman gave life to a newborn son and had her fallopian tubes and 200 cc of blood clots removed. She was transferred to the recovery room and was left alone until three hours later, when a second-year resident found her profusely bleeding and under respiratory distress. An attending doctor and a fourth-year resident evaluated the woman, diagnosed uterine atony, and conducted an emergency laparotomy, during which she lost 300 cc of blood and had her uterus removed. The woman went into cardiac arrest and died in the operating room at 1 a.m. The reported cause of death was preeclampsia. The maternal mortality review committee members determined, while I took notes, that her death could have been prevented if the woman had not been neglected in the recovery room.

All three women were diagnosed with severe obstetric complications at health facilities, where interruptions in care eventually led to their deaths. In the first case, the medical staff discharged a woman on the brink of death without fully attempting to manage the situation; in the second and third cases, the staff withheld the women's care while waiting for replacement blood donors; additionally, the staff abandoned the third woman after surgery in the recovery room. There are undoubtedly limitations in access to blood in Dominican health facilities, where 80% of blood in 2011 came from re-

placement donors, mostly family members, and in access to safe abortion, which is strictly forbidden with no explicit legal exceptions.<sup>7</sup> Despite clinical errors that maternal mortality review committees could identify in each case, the fundamental contributing determinant of these deaths was the structural state of the health system—in particular, its limited capacity to provide people-centered care that is convenient, comprehensive, integrated, longitudinal throughout the life cycle, proactive, and in which health providers are responsible and accountable to their patients.<sup>8</sup>

When I told my collaborators at the Dominican Ministry of Public Health that I was ready to share my preliminary findings, they invited me to give a formal presentation in March 2011 to a group of public health decision makers and hospital directors. Wanting to move away from the concept that clinical errors occur in a vacuum, I summarized the causes of the 49 deaths according to five systemic categories, each of which was formed by a list of criteria—the causes of the causes of the maternal deaths. Four of the categories relate to health system issues—the organization of care inside the hospitals, the lack of a culture of patient safety, the lack of guidelines for referrals and counter-referrals of women from one facility to another, and infrastructure limitations—whereas the fifth highlights the structural conditions of poverty and social inequality among the population that usually seeks care in public health facilities. The disconnect between the needs of this population and a health care delivery system that is better designed to meet the needs of medical doctors than those of women who live with multiple deprivations creates additional friction in an already rough landscape.

Drawing from the concepts of diagnostic and classification criteria for diseases—according to which a set of criteria must be met to reach a particular diagnosis—I created a list of systemic symptoms associated with maternal morbidity and mortality. My collaborators accepted the findings and began circulating “The 30 Reasons” list to other decision makers and hospital administrators.

Without exception, each maternal death

fulfilled several of the thirty criteria, bringing to the fore a health system characterized by a lack of continuum of care, a lack of accountability toward women on the part of health care providers, and the withholding of care and even outright neglect.

Unfortunately, eight years later, the list is still applicable, and casualties remain high. The number of reported maternal deaths between 2011 and 2018 kept steady at an average of 186 per year; in 2017, the last year with complete data, the maternal mortal-

TABLE 1. The 30 reasons for maternal deaths in the Dominican Republic

Categories of criteria associated with maternal mortality	The greater the number of criteria present, the higher the probability of maternal death in a woman with obstetric complications
Organization of care inside the hospital	1. Pregnant woman not assigned to a specific doctor
	2. Disconnect between outpatient (prenatal care) and inpatient (labor and other emergencies) care
	3. Lack of coordination between hospital departments
	4. Lack of teamwork and second opinions
	5. Previous medical history not considered at triage—pregnant woman becomes “first time” patient
	6. Insufficient attending doctors on duty and specialists on call
	7. Residents without supervision in charge of high-risk cases
	8. Department chiefs assigned for reasons other than merit
	9. No supervision of doctors’ compliance with norms and guidelines
	10. Premature discharge of puerperal woman from hospital
(Lack of) culture of patient safety	11. Responsibility and accountability toward woman is diffused
	12. Lack of adherence to national or hospital guidelines
	13. Insufficient assessment of vital signs, including among high-risk cases
	14. Attending doctor is unavailable (sleeping or in private practice)
	15. Hospital hierarchy emphasized over the clinical needs of woman
	16. Clinical history is incomplete or is filled out with predetermined values
	17. Responsibility to provide blood falls on the pregnant woman and her family
Referrals and counter-referrals	18. Lack of clear criteria for referrals and unjustified referrals
	19. Health care staff tell pregnant woman to go to another hospital on her own and without first checking with the referral hospital
	20. Receiving hospital lacks information about the condition of the pregnant or puerperal woman and previous management
Infrastructure	21. Insufficient availability of blood at hospital
	22. Lack of ambulances with or without doctor
	23. Irregular clean water supply in hospitals
	24. Limited number of beds in intensive care units and of incubators
Conditions of poverty and inequality	25. Anemia or malnutrition present in woman
	26. Non-adherence to treatment plan or vitamin intake due to the resale of pills to cover other costs
	27. Resort to unsafe abortion
	28. Late presentation to care
	29. Fear of disclosure of irregular residency status
	30. Failure to demand high-quality care due to unawareness of rights

ity ratio was 124 maternal deaths per 100,000 live births—much higher than the Millennium Development Goal target of 47 deaths per 100,000 live births by 2015.<sup>9</sup> Without mechanisms to redress the systemic causes of maternal mortality, the right to health will remain an elusive aspiration for many pregnant women, particularly for those living with multiple deprivations. Although a maternal death is considered a rare event in epidemiological terms, it adds up to about 7,000 deaths in Latin America each year—20 every day—usually as a result of causes that are preventable with current knowledge bases; these deaths occur disproportionately among indigenous women, Afro-descendant women, and women who live in poverty.<sup>10</sup>

### Violence against women in labor as an affront to human rights

Throughout the world, broad social exclusion and discrimination—the denial of rights, resources, and services available to dominant groups—against women, ethnic minorities, the poor, sexual minorities, and other populations whose rights are often trespassed have a significant negative impact on these populations' mental and physical health that result from stress responses.<sup>11</sup> In segmented health systems in which users of public health facilities are overwhelmingly from the lowest wealth quintiles, the clinical encounters in the public system become the locus of reproduction of unbalanced social and gender power dynamics between patients and healers (doctors, nurses, and nurse assistants) and among health care workers of different hierarchical positions; unbalanced dynamics can also result from racist treatment. In these contexts, the resulting mistreatment—which often takes a form of triple exclusion and discrimination on account of being poor, dark-skinned, and female—is systematically embedded within clinical encounters, contributing to differential health outcomes, not only as a stressor, but as a result of poor quality of care or outright neglect.<sup>12</sup>

These forms of violence are dually intolerable: they are both an infringement of human rights and fuel for inequitable health outcomes between

minority and dominant ethnicities. Given its magnitude, I decided to embrace the concept of obstetric violence, first defined in 2007 in Venezuela as “the appropriation of women’s bodies and reproductive processes by health personnel that is expressed through dehumanizing treatment, the abuse of medicalization, and the pathologization of natural processes, resulting in a loss of women’s autonomy and ability to decide freely about their bodies and sexuality, negatively affecting their quality of life.”<sup>13</sup> Such violence stems both from the actions of medical personnel and from structural issues within health care facilities and health systems.<sup>14</sup>

Most definitions of obstetric violence in Latin America emphasize the medicalization of the natural process of childbirth, as well as the unbalanced power dynamics between health personnel and women in labor that result from a combination of institutional and structural violence. In the 1990s, researchers working in Mexico started to focus on mistreatment of women during institutional childbirth—such as unnecessary cesareans or episiotomies and nonconsensual intrapartum sterilizations—as a form of violence or abuse that resembles other forms of violence against women, and to discuss the institutional and structural violence that reflect gender inequalities and power hierarchies within health facilities.<sup>15</sup>

I argue that in the Dominican Republic, physicians and nurses learn to operate within the structural limitations of the health care system by providing care for concrete evaluations and procedures, but without assuming the responsibility of the continuum of care that each woman needs. Even when their interventions may be clinically appropriate for each circumstance, the responsibility for the management of each woman is so diffused that nobody seems to be in charge. This discharge of accountability is at the heart of how health professionals can navigate, tolerate, and perpetuate the structure of the health care system and, in so doing, create the breeding ground for obstetric violence to occur. As the examples in this paper illustrate, it can be difficult to isolate the boundaries between the structural violence of a low-resourced health system failing to provide adequate care and acts of



obstetric violence that women in labor experience at the hands of clinical staff. Here, we can see that obstetric violence is perpetuated by a system but enacted by individuals, and it is precisely these individuals who hold the power to transform the right to health guaranteed by treaties and laws from rhetorical to real.<sup>16</sup>

The 30 Reasons highlight the lack of enforcement of Dominican laws aimed at guaranteeing the right to health—through timely, quality, and dignified health care—for pregnant women and at preventing violence against women in any form. In 1997, the Congress of the Dominican Republic incorporated into law the Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women of 1944 and the Convention on the Elimination of All Forms of Discrimination against Women of 1979.<sup>17</sup> Furthermore, the country's General Law of Health of 2001, in its article 14, establishes that the Ministry of Public Health should “ensure that patients receive timely care, of quality and provided with warmth, respectful of their cultural environment, their human rights and citizenship rights enshrined in constitutional regulations.” According to article 28 of this law, all people have the right to “respect for their personality, human dignity and privacy, and not to be discriminated against for reasons of ethnicity, age, religion, social condition, politics, sex, legal status, economic situation, or physical, intellectual, sensory, or any other limitations.” Additionally, article 30 defines priority groups as “people who are at and below the poverty line, within which ... priority must be given to women, with special emphasis on pregnant women, children up to the age of 14, the elderly, and the disabled.”<sup>18</sup> Pregnancy and motherhood are further protected by article 30 of the Code for the Protection of the Rights of Children and Adolescents of 2003, according to which “the state will protect motherhood. To this end, it will guarantee [women's] care through free services and programs of the highest quality, during pregnancy, delivery and the postnatal phase.”<sup>19</sup>

The Constitution of 2015 also prohibits violence against women and protects personal integrity. Article 42 states that “everyone has the right to respect

for their physical, mental, and moral integrity and to live without violence,” that “no person may be subjected to penalties, torture or humiliating procedures that involve the loss or diminution of their health, or of their physical or mental integrity,” and that “the state will guarantee by law the adoption of necessary measures to prevent, punish, and eradicate violence against women”; in addition, article 61 states that “everyone has the right to comprehensive health.”<sup>20</sup> Finally, the 2030 National Development Strategy, which was signed into law in 2012, “guarantees the right of the population to access a model of comprehensive care, with quality and warmth, which privileges the promotion of health and the prevention of disease, through the consolidation of the National Health System.” It aims to provide “ongoing training to health personnel to improve and promote the early diagnosis, care and rehabilitation of victims of gender violence and against children and adolescents,” to design “a system for supervising and sanctioning non-compliance with protocols among the clinical and administrative personnel of the health system,” to develop “health system units for gender-based violence, domestic and/or sexual violence that report to competent authorities,” and to promote “a culture of eradication of domestic violence and against women, children and adolescents.”<sup>21</sup>

The Ministry of Public Health—through the National Health Quality Policy and the Technical Regulations for the Care of Women during Pregnancy, Childbirth and Postpartum, both issued in 2013—promotes humanized, dignified, and non-discriminatory care.<sup>22</sup> According to the latter, the principles of maternal care include “respect for human rights. No pregnant woman can be obliged to receive services or care without her prior consent, expressed in a conscious way and free of coercion of any kind. The care should be performed in a responsible, dignified and respectful manner, without discrimination of any kind and with full respect for her rights as a patient.” Finally, obstetric violence was referenced for the first time in the Dominican Republic through a 2016 health regulation issued by the Ministry of Public Health. This regulation—known as the Protocol of Attention for

the Integral Management of Pregnancy, Childbirth and Postpartum in Adolescents under the Age of 15—states that during any vaginal birth, cesarean section, or abortion being experienced by an adolescent, it is essential to humanize care and to “ensure respect for their privacy and modesty, avoiding any manifestation of obstetric violence.”<sup>23</sup> Although I expect that future protocols will be updated to include women of any age, the Dominican Constitution and existing laws provide a human rights framework to protect women during pregnancy and childbirth, to guide the provision of respectful maternal health care, and to eliminate the practice of obstetric violence. The critical question becomes how to translate this aspirational framework into a health care system in which clinical staff no longer neglect their accountability toward women in labor but instead enable their attainment of the right to health.

### Scholarship with commitment: Obstetric violence as the object of study

I reject being a pacific bystander while conducting fieldwork in public health facilities, one of the few institutional spaces where, in Latin America, indigenous and Afro-descendant women are more present than women from dominant ethnic groups—the latter being understood as powerful and not necessarily greater in number. I am compelled to engage dynamically with the issue of obstetric violence by bringing it to the center of my studies, in line with the “scholarship with commitment” perspective promoted by Pierre Bourdieu and other social scientists, as well as the “praxis” concept developed by the Latin American social medicine movement.<sup>24</sup> The triple exclusion of and discrimination against women who seek care in public health facilities (on account of their being female, dark-skinned, and poor), which causes the withholding of timely and quality care, a lack of accountability mechanisms toward them, and other forms of obstetric violence, run counter a human rights-based approach.<sup>25</sup>

Unlike other Latin American contexts in which women who have been dehumanized during childbirth refrain from seeking care in the future,

Dominican women who have these three attributes that silently make them a target for obstetric violence continue to deliver in overcrowded public hospitals. In a recent study that I coauthored with Virginia Savage, in which we interviewed women who were being discharged from a public hospital right after childbirth, we found that most women who experienced obstetric violence talked about it uneventfully.<sup>26</sup> Philosophers such as Martha Nussbaum have described this form of resignation or endurance as “adaptive preference”—that is, “the preference to put up with abuse” in response to restricted options among the structurally deprived, which creates “overtly subservient tendencies”; or, as Amartya Sen has explained, “the underdog learns to bear the burden so well that he or she overlooks the burden itself.”<sup>27</sup> In our study, we found that only those women who feared for their lives or those of their newborns or who realized that they were being neglected developed a capacity to critically reflect on the coercive circumstances that could eventually cause them to die, to understand that their survival depended on hospital personnel, and to develop an autonomous rejection of obstetric violence.<sup>28</sup>

Explaining the suffering of women will not, on its own, prevent obstetric violence. However, the visualization of obstetric violence rendered by research offers two key benefits. First, it contributes to advocacy for the adoption of human rights-based approaches that protect women during pregnancy and childbirth when none exist. Second, it contributes to the monitoring and documentation of human rights standards “to deepen our understandings of the nature of violations, their causes and effects, and the development of more comprehensive human rights standards to guide remedy and redress measures” and to create accountability measures within health systems to prevent obstetric violence.<sup>29</sup> In Proyecto Mujer al Centro (Pregnant Women-Centered Care Project), we are studying the associations among obstetric violence, adverse maternal and child health outcomes, and inequity in the right to health—and, by doing so, we aim to dispel the myth that obstetric violence in a health care setting is uneventful.

## Acknowledgments

I thank Marilyn Heymann for her diligent assistance with the coordination and analysis of my maternal mortality study in the Dominican Republic, Naiara Appaix-Castro for her critical review of this paper, Rachel Hall-Clifford for her suggestions, and Dr. José Mordán for his continuous support of my research on behalf of the Ministry of Public Health of the Dominican Republic and for our fruitful conversations on the issue of obstetric violence.

## Note

All translations from Spanish to English were performed by the author.

## References

1. A. Castro, A. Heimbürger, and A. Langer, *Iatrogenic epidemic: How health care professionals contribute to the high proportion of Cesarean sections in Mexico* (Cambridge, MA: David Rockefeller Center for Latin American Studies at Harvard University, 2003); A. Castro, "Contracepting at childbirth: The integration of reproductive health and population policies in Mexico," in A. Castro and M. Singer (eds), *Unhealthy health policy: A critical anthropological examination* (Walnut Creek, CA: Altamira Press, 2004), pp. 133-144; A. Castro, Y. Khawja, and I. González-Núñez, "Sexuality, reproduction, and HIV in women: The impact of antiretroviral therapy in elective pregnancies in Cuba," *AIDS* 21/S5 (2007), pp. 49-54; A. Castro and U. Sandesara, *Integración de la atención prenatal con los procesos de detección y manejo clínico del VIH y de la sífilis en el Perú / Integration of prenatal care with the testing and treatment of HIV and syphilis in Peru* (Lima: Socios En Salud, Ministry of Health of Peru, UNAIDS, and UNICEF, 2009); M. Connolly, C. Bautista, and A. Castro, "Utilización del formulario de la historia clínica perinatal y neonatal en República Dominicana," *Boletín del Centro Nacional de Investigaciones en Salud Materno Infantil* 19/3 (2009), pp. 17-23; E. Pérez-Then, M. Miric, and A. Castro, *Integración de la atención prenatal con los procesos de detección y manejo clínico del VIH y de la sífilis en la República Dominicana* (Santo Domingo: Centro Nacional de Investigaciones de Salud Materno Infantil, Harvard Global Health Institute, Ministry of Public Health, Consejo Presidencial del Sida, UNICEF, 2011); A. Castro, J. R. Espinoza, M. E. Quintana, et al., *Integración de la Atención Prenatal con los Procesos de Detección y Manejo Clínico del VIH y de la Sífilis en Nicaragua* (Managua: UNICEF, 2010); A. Castro, "En estado de buena esperanza: Análisis de la experiencia reproductiva en mujeres con VIH en Cuba," in J. A. Haro (ed), *El planteamiento de una epidemiología sociocultural: Un diálogo en torno a su sentido, métodos y alcances* (Buenos Aires: Lugar Editorial and El Colegio de Sonora, 2011), pp. 155-168; Ö. Tunçalp, C. Stanton, A. Castro, et al., "Measuring coverage in MNCH: Validating women's self-report of emergency cesarean sections in Ghana and the Dominican Republic," *PLoS ONE* 8/5 (2013), p. e60761; A. Ettenger, T. Bärnighausen, and A. Castro, "Health insurance for the poor decreases access to HIV testing in antenatal care: Evidence of an unintended effect of health insurance reform in Colombia," *Health Policy and Planning* 29/3 (2013), pp. 352-358; A. Castro and V. Savage, "Obstetric violence as reproductive governance in the Dominican Republic," *Medical Anthropology* 38/2 (2019), pp. 123-136.
2. Castro (2004, see note 1).
3. A. Castro, "Commentary: Increase in caesarean sections may reflect medical control not women's choice," *British Medical Journal* 319 (1999), pp. 1401-1402.
4. Pérez-Then et al. (see note 1).
5. Ministry of Public Health of the Dominican Republic, *Perfil de la salud materna: ODM 5; República Dominicana* (Santo Domingo: Ministry of Public Health, 2013).
6. Ibid.
7. Ministry of Public Health of the Dominican Republic, *Política nacional de sangre* (Santo Domingo: Ministry of Public Health, 2014); Guttmacher Institute, *Fact Sheet: Abortion in Latin America and the Caribbean* (New York: Guttmacher Institute, 2018).
8. World Health Organization, *World health report: Primary health care now more than ever* (Geneva: World Health Organization, 2008); M. P. Fort, D. E. Grembowski, J. C. Verdugo, et al., "Implementation and progress of an inclusive primary health care model in Guatemala: Coverage, quality, and utilization," *Pan American Journal of Public Health* 30/3 (2011), pp. 217-224; R. Álvarez Sintés, *Medicina general integral* (Havana: Editorial Ciencias Médicas, 2008).
9. Ministry of Public Health of the Dominican Republic, *General directorate of epidemiology weekly bulletins* (Santo Domingo: Ministry of Public Health, 2011-2019).
10. United Nations Children's Fund and Tulane University, *Health equity report 2016: Analysis of reproductive, maternal, newborn, child, and adolescent health inequities in Latin America and the Caribbean to inform policy making* (UNICEF: Panama City, 2016).
11. A. Castro, V. Savage, and H. Kaufman, "Assessing equitable care for indigenous and Afrodescendant women in Latin America," *Pan American Journal of Public Health* 38/2 (2015), pp. 96-109.
12. A. Castro, "Health and inequality," in H. Callan (ed), *The international encyclopedia of anthropology* (Hoboken, NJ: Wiley-Blackwell, 2018); Castro et al. (2015, see note 11).
13. Bolivarian Republic of Venezuela, *Ley orgánica sobre el derecho de las mujeres a una vida libre de violencia* (2007).
14. V. Savage and A. Castro, "Measuring mistreatment of women during childbirth: A review of terminology and method-

ological approaches,” *Reproductive Health* 14/138 (2017), pp. 1–27.

15. Castro (1999, see note 3); R. Castro, *La vida en la adversidad: El significado de la salud y la reproducción en la pobreza* (Cuernavaca: CRIM/UNAM, 2000); R. Castro and J. Erviti, “Violations of reproductive rights during hospital births in Mexico,” *Health and Human Rights* 7/1 (2003), pp. 90–110; G. Freyermuth, “Antecedentes de Acteal, muerte materna y control natal ¿Genocidio silencioso?,” in R. Hernández (ed), *La otra palabra. Mujeres y violencia en Chiapas, antes y después de Acteal* (Mexico City: Centro de Investigaciones y Estudios Superiores en Antropología Social, 1998), pp. 63–83; Red por la Salud de las Mujeres del Distrito Federal, *Tribunal para la defensa de los derechos reproductivos: Dossier de casos* (Mexico City: Red por la Salud de las Mujeres del DF, 1996); C. Rincón, “Violaciones a los derechos reproductivos por parte de las instituciones médicas en México,” in C. Bunch, C. Hinojosa, and N. Reilly (eds), *Los derechos de las mujeres son derechos humanos: Crónica de una movilización mundial* (Mexico City: Edamex, 2000), pp. 115–118.

16. G. Backman, P. Hunt, R. Khosla, et al., “Health systems and the right to health: An assessment of 194 countries,” *Lancet* 372/9655 (2008), pp. 2047–2085.

17. National Congress of the Dominican Republic, *Ley No. 24-97 que introduce modificaciones al código penal y al código para la protección de niños, niñas y adolescentes* (1997).

18. National Congress of the Dominican Republic, *Ley 42-01: Ley general de salud* (2001).

19. National Congress of the Dominican Republic, *Ley 136-03: Código para la protección de los derechos de los niños, niñas y adolescentes* (2003).

20. Government of the Dominican Republic, *Constitución Política de la República Dominicana* (2015).

21. National Congress of the Dominican Republic, *Ley 1-12: Estrategia nacional de desarrollo 2030* (2012).

22. Ministry of Public Health of the Dominican Republic, *Política nacional de calidad en salud* (2013); Ministry of Public Health, *Reglamento técnico de atención a la mujer durante el embarazo, el parto y el puerperio* (Santo Domingo: Ministry of Public Health, 2013).

23. Ministry of Public Health of the Dominican Republic, *Protocolo de atención para el manejo integral del embarazo, el parto y el puerperio en adolescentes menores de 15 años* (Santo Domingo: Ministry of Public Health, 2016).

24. P. Bourdieu, “Pour un savoir engagé,” *Le Monde Diplomatique* (February 2002), p. 3; D. Galeano, L. Trotta, and H. Spinelli, “Juan César García and the Latin American social medicine movement: Notes on a life trajectory,” *Salud Colectiva* 7/3 (2011), pp. 285–315; E. Granda Ugalde, *La salud y la vida, Volumen 1* (Quito: Pan American Health Organization, 2009); J. Breilh, “La epidemiología crítica: Una nueva forma de mirar la salud en el espacio urbano,” *Salud Colectiva* 6/1 (2010), pp. 83–101; P. Farmer, *Pathologies of power: Health, human rights, and the new war on the poor* (Berkeley: University of California Press, 2003).

25. S. Miller, M. Cordero, A. L. Coleman, et al., “Quality of care in institutionalized deliveries: The paradox of the Dominican Republic,” *International Journal of Gynecology and Obstetrics* 82/1 (2003), pp. 89–103; J. Ruminjo, C. Cordero, K. J. Beattie, and M. N. Wegner, “Quality of care in labor and delivery: A paradox in the Dominican Republic; Commentary,” *International Journal of Gynecology and Obstetrics* 82/1 (2003), pp. 115–119; G. La Forgia, R. Levine, A. Diaz, and M. Rathe, “Fend for yourself: Systemic failure in the Dominican health system,” *Health Policy* 67/2 (2004), pp. 173–186; J. Foster, R. Burgos, C. Tejada, et al., “A community-based participatory research approach to explore community perceptions of the quality of maternal–newborn health services in the Dominican Republic,” *Midwifery* 26/5 (2010), pp. 504–511; Castro and Savage (2019, see note 1).

26. Castro and Savage (2019, see note 1).

27. M. Nussbaum, “Adaptive preferences and women’s options,” *Economics and Philosophy* 17 (2001), pp. 67–88; R. Terlazzo, “Conceptualizing adaptive preferences respectfully: An indirectly substantive account,” *Journal of Political Philosophy* 24/2 (2016), pp. 206–226; A. Sen, *Resources, values and development* (Oxford: Basil Blackwell, 1984).

28. Castro and Savage (2019, see note 1).

29. R. Khosla, C. Zampas, J. P. Vogel, et al., “International human rights and the mistreatment of women during childbirth,” *Health and Human Rights Journal* 18/2 (2016), pp. 131–143.





# The Lived Experience of Global Public Health Practice: A Phenomenological Account of Women Graduate Students

COREY MCAULIFFE, ROSS UPSHUR, DANIEL W. SELLEN, AND ERICA DI RUGGIERO

## Abstract

There is a dearth of research that aims to understand graduate students' lived experience of global health practice. Difficulties, distress, and trauma occur before and after these students' placement abroad, and they often increase when returning home. Moreover, few articles address the increased vulnerabilities faced by women, such as sexual violence and gender-based discrimination. We conducted a phenomenological study to understand the lived experience of Canadian and US women graduate students participating in global public health practice. Eight participants participated in 21 in-depth interviews, while 17 participants created 35 lived experience descriptions through a guided writing exercise. Our findings reveal participants' underlying discomfort with privilege while conducting fieldwork abroad, as well as depressive feelings once they return home. According to participants, while their global health fieldwork challenged previous ways of thinking and being, limited spaces and avenues for openly sharing these processes contributed to mental health challenges. Participants reported that these interviews were their first opportunity to fully share their global health experiences. Based on our analysis of these shared experiences, we argue that academic institutions participating in global health should provide appropriate and accessible resources, adequate financial compensation, safe spaces for authentic conversations, and time for processing experiences throughout the research cycle and especially in the months and years following fieldwork.

---

COREY MCAULIFFE, MPH, is a PhD candidate in the Division of Social and Behavioural Health Sciences, Dalla Lana School of Public Health, University of Toronto, Canada.

ROSS UPSHUR, MA, MD, is head of the Clinical Public Health Division, Dalla Lana School of Public Health, University of Toronto, Canada.

DANIEL W. SELLEN, MA, PhD, is director of the Joannah and Brian Lawson Centre for Child Nutrition, University of Toronto, Canada.

ERICA DI RUGGIERO, MHSc, PhD, is director of the Office of Global Public Health Education and Training, Dalla Lana School of Public Health, University of Toronto, Canada.

Please address correspondence to Corey McAuliffe. Email: [corey.mcauliffe@mail.utoronto.ca](mailto:corey.mcauliffe@mail.utoronto.ca).

Competing interests: None declared.

Copyright © 2019 McAuliffe, Upshur, Sellen, and Di Ruggiero. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted noncommercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

## Introduction

*Content warning: this article includes content and references pertaining to traumatic and distressing experiences of individuals, including sexual violence.*

With the growth of global health programs across the United States and Canada, more students are seeking out international fieldwork experiences.<sup>1</sup> Master's and doctoral programs are foundational spaces for learning and preparation for practice. However, the short- and long-term effects of this work are unknown, and our understanding of student experience remains inadequate. Since global health is an interdisciplinary field of study, we reviewed the literature on all (non-clinical) graduate students' participation in global health fieldwork within the Global South.<sup>2</sup> We found no identifiable literature pertaining to public health graduate student experience; however, the literature illustrates that graduate students participating in global health fieldwork face difficult and challenging situations before, during, and after fieldwork.<sup>3</sup> While some risk and discomfort is implicitly assumed during fieldwork, students identified traumatic and distressing experiences that were silenced and suppressed and that left them feeling isolated, often exacerbated once they returned home.<sup>4</sup> Fieldwork may be perceived as a positive experience overall, but it can also leave students with feelings of anxiety, depression, and, in extreme instances, post-traumatic stress disorder (PTSD).<sup>5</sup> Numerous cases of sexual violence and harassment against women participating in global health fieldwork are documented, but there is a paucity of accounts specific to public health students' experiences.<sup>6</sup> The primary researcher's own tacit beliefs of safety in the workplace were challenged and forcibly deconstructed after a personal traumatic experience during academic global health fieldwork. This occurrence magnified a void regarding how others have dealt with similar experiences. This paper aims to break that silence and suggests that universities have an ethical duty of care for all students.

### *Personal and professional impact on students*

Many global public health training opportunities

in the Global South are located in unfamiliar or precarious environments, where students regularly undertake unpaid or underpaid work with limited support and resources.<sup>7</sup> Considerations for student safety are needed before, during, and following fieldwork. However, attention appears to be disproportionately focused on the period prior to departure, even though many professionals argue that re-entry is the most important stage of the international experience.<sup>8</sup> Moreover, university-based pre-departure trainings can be missing or inadequate.<sup>9</sup> According to Amy Pollard, not one student from her multi-university study found their pre-departure training to be satisfactory, claiming that it was "useless" and that they received "zero preparation for actual fieldwork."<sup>10</sup> Within our study, half of the interview participants reported that there was no pre-departure training available or they had not been made aware of one.

Once home, students often receive requests to recount their experiences in both professional and personal settings. There appears to be institutional and personal bias toward documenting positive, transformative outcomes, often cultivated and oriented for curriculum vitae, awards, and scholarship opportunities.<sup>11</sup> This is more challenging in a context where graduate students are not in positions of power (compared to faculty members, field site supervisors, and administrators), which can lead to feelings of isolation and being overwhelmed, the exploitation of labor, and issues of sexual harassment and assault.<sup>12</sup> Moreover, students may suppress negative and traumatizing experiences, given that they are often precariously employed, further limiting safe academic spaces where they may openly and vulnerably share.<sup>13</sup>

### *Gendered impacts on women in global health*

Women in global health face additional stereotypes, oppression, reproductive health barriers, gender inequities, and sexual violence compared to their male counterparts. In relation to family planning (such as (in)fertility, childbearing, and parenting), some women face further strains, which can be intensified when working in malaria- or Zika-endemic countries.<sup>14</sup> Women may be forced to

disclose sensitive information that they otherwise are not ready to share. Gender inequities further affect women through increased financial stress stemming from disproportionate pay and labor.<sup>15</sup>

While numerous cases of sexual violence and harassment against women conducting global health fieldwork have been documented, Valery Ridde et al. note that the “issue has received little attention in academic global health.”<sup>16</sup> A report by the Women in Global Health Research Initiative found that “twenty-six percent of women report having experienced unwanted physical contact while doing international field research.”<sup>17</sup> The *Survey of Academic Field Experience: Trainees Report Harassment and Assault* further found that “64% of female respondents experienced sexual harassment, while 20% were victims of sexual assault” and that the “perpetrators were most often senior male research team members.”<sup>18</sup> Women’s future academic careers are negatively affected by sexual violence through increased mental health challenges and decreased productivity, which further constrains funding opportunities.<sup>19</sup> While sexual violence remains prevalent in US and Canadian academic settings, current programs and policies have started to address this; however, additional attention is required, beyond the merely local institutional level, to reduce sexual violence within the global health field. Research also shows that repercussions go beyond women who are targeted by harassment, affecting colleagues and creating a toxic work environment.<sup>20</sup> These occurrences continue to be highly stigmatized, silenced, and inadequately addressed, which can lead to varied emotional, spiritual, physical, and mental health outcomes.<sup>21</sup> Our research study revealed multiple effects on women who underwent such experiences, including (but not limited to) fear, depression, anxiety, isolation, self-blame, and PTSD.

## Methodology

This research study used philosophical, theoretical, and methodologically aligned qualitative research to better understand human behavior and embodiment. Our study was situated within Max

van Manen’s qualitative methodology known as “phenomenology of practice.”<sup>22</sup> This hermeneutic interpretive approach aims to better understand lived experience, privileging participant knowledge through their experience of living- or being-in-the-world, and offering a holistic perspective that is inclusive of emotional, embodied, existential, and pathic ways of knowing.<sup>23</sup>

### *Phenomenology of practice*

A phenomenology of practice seeks to identify “practical acts of living, accessed through ‘narratives’ (interviews and observations) to reveal meaning,” increasing awareness of lived experience, “rather than providing theory for generalization or prediction of phenomena.”<sup>24</sup> This tension exists for students, as what is learned in the classroom is often quite different from what is required in fieldwork practice. Phenomenological accounts offer an opportunity to reflect on practice, challenging the supremacy of cognitive understanding, by embracing a deeper empathic sense of being-in-the-world.<sup>25</sup> Consequently, phenomenology can affect an individual’s experience or an institution’s understanding of the phenomenon, as it may offer new meaning structures, language for a foreign experience, and new ways to describe, conceive of, and respond to global health fieldwork.<sup>26</sup>

### *Research question*

Our central research question was the following: What is the lived experience of US and Canadian women graduate students participating in global public health practice? We sought to understand experiential opportunities and challenges, while creating space for open and honest dialogue on global public health practice.

## Methods

This qualitative study involved the collection of lived experience descriptions (LED) through in-depth phenomenological interviews (IDPIs) and a guided writing exercise (GWE). A LED is a “vivid textual account of an experience” that aims to recall “a particular instance of an experience

in concrete personal terms avoiding abstraction (possible introductions, rationalizations, causal explanations, generalizations, or interpretations).<sup>27</sup> To not further silence or suppress students' experiences, participation in the GWE was open to any eligible participant.

*Study setting and participants*

We conducted our study in Canada and the United States between January and October 2018. Inclusion criteria responded to the temporal and cultural context of global public health practice (see Table 1).

*Participant recruitment and participation*

We employed purposive sampling to recruit participants, through email and social media recruitment. Of the 49 women who expressed interest, 4 were ineligible. While 13 potential participants completed an IDPI pre-interview, only 8 were selected to participate in the IDPIs. Seventeen participants contributed through the GWE, submitting 35 LEDs. Since in-person interviews are favorable to building trust, our travel feasibility, financial means, and accessibility to participants influenced our choice of study participants and interview locations. Those outside of North America were invited to participate in the GWE.

Given that representativeness is not the objective of phenomenology, we selected eight participants from the pre-interviews to allow for multiple (two to three) IDPIs with each participant. Heterogeneity was maximized through the selection process (for example, university attended, country of origin, length of time spent abroad, country of fieldwork,

and area of expertise) within a fairly homogenous group. From the IDPIs, participants came from varied backgrounds (see Table 2). We did not explicitly collect sociodemographic data (for example, race, age, socioeconomic status, sexual orientation), as our research aimed to better understand participants' lived experiences. Participants' stories reflect experiences in more than 20 countries, including sub-Saharan Africa, Latin America, and Southeast Asia. The 25 study participants attended a total of 14 different universities for master's or doctoral studies, completing their graduate-level international fieldwork between 2010 and 2016.

*Data creation, analysis, and interpretation*

Informed by van Manen, our hermeneutic phenomenological analysis sought to explore participants' experiences through the co-construction of narrative accounts, recognizing the self and other as entwined.<sup>28</sup> While participants deeply engaged with their own lived experiences, the primary researcher acted as a "central figure who influences the collection, selection, and interpretation of data"; thus, our research was "regarded as a joint product of the participants, the researcher, and their relationship: It [was] co-constituted."<sup>29</sup> Our data generation focused on detailed descriptions rather than cognitive considerations or reflections of participants' experiences.<sup>30</sup>

Our analytic process aligned with Linda Finlay's four key processes to phenomenological sensibility: "seeing afresh, dwelling, explicating, and languaging."<sup>31</sup> By "seeing afresh," we incorporated a deep reflexive position, stepping *back*

TABLE 1. Participant inclusion and exclusion criteria

<b>Inclusion criteria</b>
Self-identify as a woman
Self-identify as Canadian or from the United States
Graduate-level studies took place in a Canadian or US academic institution
Research/work focuses on global public health practice
Participated in global public health practice in a low- or middle-income country between 2000 and 2016 while studying public health at the graduate level (master's or doctoral)
Participated in fieldwork abroad for at least four consecutive weeks
<b>There are no exclusion criteria</b>

from the data rather than stepping *away* from it. In “dwelling,” we read and re-read (listened and re-listened to) the data as a whole and in segments, identifying particular points, meanings, and preliminary themes from personal accounts. This was supported through reflective inquiry using five existential guides (explained below).<sup>32</sup> Through “explicating,” we created overarching themes, meaning structures, and stories. In phenomenology, a theme is “much less a singular statement (concept or category) than an actual description of the structure of a lived experience,” as no one account can capture the totality of an experience.<sup>33</sup> Our stories were thus rooted in “salient excerpts that characterize specific common themes or meanings across informants” rather than specific accuracy toward the experience of one individual.<sup>34</sup> As part of our interpretive analysis, we crafted stories from verbatim IDPI transcripts to draw attention to multiple or hidden meanings.<sup>35</sup> Exemplars from these stories are highlighted in the findings below. We used “language” through writing and re-writing that was rooted in existentiality, not theory.<sup>36</sup> This type of qualitative writing identifies an openness to other plausible experiences, focusing on iconic (recognizable) as opposed to empirical validity. Such shared experiences offer an emotional and compelling technique that allows readers to better comprehend lived experiences, sometimes more effectively than lived life.<sup>37</sup> Throughout our study, we incorporated reflexivity through reflexive journaling, field notes, data co-creation, and regular in-depth conversations with colleagues.

### *Pathic knowledge and existential guides*

An examination of a person’s pathic knowledge is derived from their pre-cognitive habits, *empathic* or

*sympathic* understandings, gut feelings, memories, and situational experiences. Pathic knowledge, as a phenomenological concept, captures the “non-cognitive” and emotional ways in which we know, necessitating a shift to conceptualize emotions as rational.<sup>38</sup> Thus, phenomenological stories help shed light on things that are taken for granted, hidden, silenced, or at times suppressed.<sup>39</sup> We applied Maurice Merleau-Ponty and Max van Manen’s five existential guides—relationality, corporeality, spatiality, temporality, and materiality—to allow for the identification of what is often perceived as ambient or background noise.<sup>40</sup> Since these existential ways of knowing are often tacit, our application and guided reflection influenced our research question, data-creation tools (interview and guided writing guides, use of audio recorders, and use of computers), transcription methods, participant and researcher experiences, and analytic processes (reflexively, conceptually, and thematically).

### *Ethical considerations*

This study was approved by the University of Toronto’s Research Ethics Board. Formal written consent was obtained from each participant. Consent was understood to be ongoing and continually negotiated and was thus verbally revisited at the beginning of each additional interview. Participants were free to withdraw from the study at any point; however, no participants withdrew.

### Findings and implications: Overarching themes

The key themes that emerged in our study include discomfort with privilege, mental and physical health challenges, sexual violence and harassment,

TABLE 2. Available socio-demographic data for IDPI participants

<b>Ethno-racial identities:</b> black and white African ancestry, white European ancestry, Chinese ancestry
<b>Immigration:</b> immigrated as a child from Africa; first generation (parents born elsewhere)
<b>Language fluency in country of fieldwork:</b> native, proficient, conversational, none
<b>Duration of time in academic fieldwork:</b> 6 weeks–9 months
<b>Frequency of global health experience abroad (academic and work):</b> 1–30+ times
<b>Financial status:</b> varied from limited (for example, relying on loans, incurring debt), to fully funded, or having personal access to sufficient financial needs



witnessing or experiencing violence, reproductive health and fertility, travel safety and transportation, a lack of preparedness, financial burdens and stress, peer relationships as protective, and being heard. Our findings show that while the experience of global public health practice by women graduate students is varied and complex, participants have deep-rooted commonalities. While individual experiences were unique, emotional reactions and responses to these experiences appear cross-cutting among multiple—or at times, all—participants interviewed. Many of these underlying responses or deep-seated feelings (that is, themes) also appeared in the GWE.

This article covers three overarching themes (sexual violence and harassment, discomfort with privilege, and being heard), and one subtheme within mental and physical health challenges (depression). Each theme is described below, with exemplars. At the end of each exemplar we list the participant's initials; the region where the person undertook fieldwork (note that the East African region includes the Horn of Africa); and the data source for the exemplar (IDPI or GWE). These findings reflect the dynamic and evolving understandings of global public health practice.

### *Sexual violence, harassment, and gender discrimination*

Participants experienced various forms of sexual violence, including assault, harassment, gender discrimination, and fear of personal safety due to their sexual orientation. Participants experienced these forms of violence from individuals in positions of power (for example, preceptors, doctors, government officials, and organizational directors), from colleagues, in public spaces, and in communities where they lived.

*My first few global health experiences were filled with sexual harassment and violence, from men in positions of authority. It took me a long time to see that pattern and realize I didn't do anything wrong. I was always trying to fix myself to fit into global health. Talking to other women who had similar experiences made me feel like maybe we are not the problem. (EM, East Africa, IDPI)*

*One afternoon, a woman made a joke about me marrying my preceptor, who was the head of a women's empowerment NGO, so that he could move to North America with me. I was very uncomfortable and my whole body tensed as each muscle flexed. My preceptor started cracking up and joined in on the joke. The experience stayed with me throughout my practicum, especially when my preceptor made very sexist comments about women. When I would get to work and he wasn't there, I felt relieved. (SS, Southern Africa, GWE)*

*While in Central America, my driver, who I'd respected, pulled me behind a door and started kissing me. I was startled. I pushed him away and kept my distance from him afterwards. I remember thinking, "Whoa. I don't know what just happened, why that happened, or how to avoid having that happen again." After it happened, I never told anyone about it, and blamed myself. Now, with #MeToo, I realize it's really common. (RK, Central America, IDPI)*

Women who reported experiencing sexual violence or gender discrimination often noted that they did not share this information with others, as they felt they had done something wrong or could have prevented the experience from happening. Women further reported that they attempted various mitigation tactics (for example, wearing oversized clothes, carrying pepper spray, taking different routes home each day, and wearing a fake wedding ring), especially when traveling alone.

Two participants who identified as LGBTQ noted fearing for their safety in countries where homosexuality was illegal.

*I asked a local clinician to complete a specific study-related questionnaire. He made a snide remark that he would only do it if I took him out for a drink. I said no. So he did not complete the questionnaire. When my co-investigator found out, he made a joke about my sexuality, "Tell him you like people who wear dresses." This made me nervous for my safety, as homosexuality is a criminal offense. Due to this experience, I returned home early. (DA, Southern Africa, GWE)*

*After being followed through the woods by a man, having several cabbies pay undue attention to*

*me, and the NGO's director sexually harass me, my anxiety heightened into terror. The sexual harassment and re-triggering of a sexual assault turned my stomach into anxious knots. Like a ball of yarn unraveling, I realized why I was coming apart so quickly: I wasn't able to be myself. It was a toxic mix—being a woman and having no local friends or support. When my partner came to visit, I had to conceal my love and affection for her, as homosexuality was illegal in the country. I had to pretend to have a boyfriend and speak about him instead of her. I realized how quickly my identity was removed. It felt like everything that was me, was not allowed. (GN, South Asia, GWE)*

It is evident from the exemplars above that women who identify as LGBTQ experience intersectional oppressions. GN reported that she shared her story with the primary researcher only because she felt she could trust her. DA also expressed that she felt willing to share her story due to the primary researcher's student status. Due to the trauma of GN's fieldwork in South Asia, she stated, "I do not want to go back into the field. I do not want to continue in global health research." As we aimed to capture the experiences of women in general, it is imperative to gain further and deeper insight into the experiences of LGBTQ individuals participating in global health, in order to create a safe and inclusive work environment for all.

### *Discomfort with privilege*

Discomfort due to privilege was discussed by every IDPI participant and also raised in many guided writing exercises, despite participants' different backgrounds and experiences. This was most often expressed in reference to participants' position as residents of the Global North, and it included similar feelings from all participants, even those who completed fieldwork in countries of familial origin. Participants questioned the inequities they witnessed, why their work was deemed more valuable than that of local community members, and the benefits they received while abroad and once home. These feelings of inequity also led participants to recognize a fissure or dissonance in their "two worlds."

*My fieldwork left me questioning: What do I do with*

*this information? Why are women in this country going through so much? Why do I have the privileges I have? Even though I am not really privileged in North America, when I did my fieldwork, it was clear how privileged I was. Sitting in between these two worlds is really hard. Some of these women have the same name as me, or our family members are cousins. But their parents weren't able to get out like my parents. That one thing alone means we lived completely different lives. I could have been that woman. (GF, East Africa, IDPI)*

The concept of having one foot in two different worlds was held by multiple participants, regardless of whether they had familial relations in their country of fieldwork. They felt like they were simultaneously living two lives, never feeling whole.

*I feel like I'm living two lives right now. I have one full life there: friends, family, who I work with, where I work, and what I spend my time doing. And I have all of that here too. It's completely disintegrated. I try to integrate them, but it doesn't work. So much of my heart, mind, body, spirit and energy is still over there. The more I go and come back, I am only half a person. (TA, West Africa, IDPI)*

Participants reported experiencing negative mental health impacts—including depression, loss of energy, and disconnect from previous support systems—as a result of their unease with privilege and its effect on their sense of self (two lives) and spatial and geographic groundedness (two worlds). This unease further affected their fieldwork experiences and left them questioning the appropriateness of unexpected benefits during fieldwork.

*I stayed with family members while doing my fieldwork. They are really well off. They had all these people working for them, and I benefited from that every day. I felt so uncomfortable. It was mainly young people who aren't going to be educated, who are cooking my food, cleaning my clothes, and getting me any little thing that I need. I already felt so privileged being there. I didn't want to feel that privilege on top of it. I thought about that every single day. Here I am with my little pieces of paper, doing my research, and talking to people. That's my work. And they're waking up at dawn to cook food, make tea, make bread, serve people, sweep*

*the entire compound, and clean up after everyone. I found that really hard. It made me think, "How is my work of more value than the work they're doing? But they work way harder than me." (GF, East Africa, IDPI)*

Many participants experienced feelings of depression and frustration but could not speak freely to others in academic settings. Feelings of guilt, including professional benefits, were exacerbated when they returned home. This was acutely felt when these women published and presented their findings, recognizing the juxtaposition between fancy conference hotels and the conditions of the communities where they conducted their research. Their hyperawareness of inequities led some participants to feel that their difficulties were invalid or not "bad enough" to warrant the time and space needed for processing their experiences. While these challenges have been documented in the humanitarian aid literature, their impact on future practice has not previously been studied.<sup>41</sup> In addition, most of the relevant writing on global health fieldwork has focused on anxiety and isolation rather than depression.<sup>42</sup>

### *Mental health challenges: Depression*

Participants reported a wide variety of mental health challenges, including witnessing or experiencing trauma or violence, sensitive data collection, moral distress, and a lack of time to process and reflect on experiences. Further mental health challenges related to returning home included anxiety, feelings of being overwhelmed (connected to school), panic attacks, and PTSD. Many participants' experiences of discomfort with privilege and feelings of depression also intensified as they returned home.

*The depression I felt after my global health experience was a coming to terms with the harsh realities and stark disparities of the world. I was trying to figure out how to make sense of the suffering I witnessed, while coming back to my shiny city and all the comforts of a really nice life in North America. (RK, Western Africa, IDPI)*

*For those who sought out mental health services, they often did not know how to proceed or where*

*to find accessible and affordable services. As shown below, some attempted to utilize university services but felt that their efforts were dismissed.*

*People asked me, "So, how was it? Tell me all the things." I couldn't articulate to someone who wasn't there what it was like. I should've been happier to be back, but I was in a weird funk. It lasted a few months, to the point where I thought, "This is not okay. I need to seek help." Not because I was worried, I was just really depressed every day. It was gross. At one point, I went to the university and tried to get a referral to a counselor, and it was brutal. There was nothing. I was reaching out. I was trying to seek help, and it was not taken seriously at all. (HK, East Africa, IDPI)*

When counseling services were offered to HK, it was not until four months later. Meanwhile, the only other immediate option available to her was to call the university's crisis hotline, which was not appropriate for her needs. RM (South America, IDPI) reported never seeking out university counseling, as it was common knowledge on campus that appointments were available only if booked months in advance. Some participants reported not seeking outside support as they went through the process of trying to understand what they had witnessed or experienced, while others reported not feeling ready to share, being unsure of whom to share it with, or feeling that others would not understand their experience. Participants noted that these experiences shifted their sense of self and at times exacerbated mental health challenges. For example, once returned home, data analysis led some participants to feel overwhelmed, isolated, anxious, and re-traumatized.

*After I came back was the most depressing period of my life. It was gray and cold out. I felt disconnected, because we didn't have classes anymore. All my close friends had moved, and all I did was work on my thesis. I didn't have much human interaction. I felt so depressed. I didn't want to wake up. Certain stories were at the forefront of my mind every day. The fact that my research was my sole responsibility was really tough. I was alone constantly. (GF, East Africa, IDPI)*

*Arriving home, I was distraught from day one. I*

*was angry at people around me. I picked fights. I boiled inside every time a friend asked me how my "trip" was, as if I'd gone on vacation. As I returned back to school and started my data analysis and write up, anxiety and depression set in. (GN, South Asia, GWE)*

A fundamental shift in one's self was a common experience reported by participants, who expressed feeling alone and not understood. This idea is connected to other participants' expression of simultaneously living in "two worlds." For some, returning to the data meant facing memories from a challenging time period. For others, the experience of analyzing data was connected to a lack of time and space in which to process and realize the depth of their experiences and emotional reactions to them. Depressive feelings are temporally bound and often triggered when participants return home, especially once they revert back to a typical (past) schedule. While the intensity of depressive feelings seems to lessen with time, these feelings can continue to drain energy as they play softly in the background.

### *Being heard*

In RK's first interview, she identified feeling that her global health experiences were very positive overall. In our second interview, after being asked how she felt after the first interview, she replied:

*I'm surprised by how much these conversations brought up things I hadn't thought about in a long time, and in ways I hadn't considered. It brought up emotions I wasn't anticipating. I felt, "Wow, this is some stuff I haven't fully processed yet," when I believed I had finished processing it years ago. I'm grateful for the opportunity to reflect, and surprised at how much it impacted me, even days later. I hadn't thought my experiences were intense. I had compartmentalized them and thought of them as normal global health experiences. But then again, it is the norm for global health. But it's not normal. Or not the way it needs to be. (RK, South America, IDPI)*

RK's reflection elucidates an important conception of the global health experience—what is *normal*? Others recognized challenging or traumatizing

fieldwork experiences through accumulating "badges of honor" or "joining the club." Women are often reluctant to identify these experiences as negative for fear that they "failed" the test.<sup>43</sup> In this way, participants sometimes found ways to make the stories palatable or funny—or, more often, they remained silent or shared their stories selectively.

Many participants related later in the IDPIs that the interviews were the first opportunity they had to fully share their experience. While most had been in settings where they were able to share a handful of core stories, many participants never found a welcoming or acceptable space to share their whole experience. This included those who sought (and accessed) counseling, who reported feeling that their counselor was ill equipped or asked irrelevant questions.

*This process is therapeutic. It's rare that I get to speak to somebody that has traveled, let alone to a similar part of the world and has the same training or understanding of global health. I really appreciate your listening. A lot of the things we talked about, I've never talked to anyone about. Little pieces, but never as much to any one person, ever. It's heavy. I still deal with a lot of it. I feel like I'm drowning in it. (TA, West Africa, IDPI)*

Participants expressed how important it was to openly share their story beyond a clinical mental health framing, noting the positive benefits experienced through this research study.

*The importance of your research is clear for me. No one gets the opportunity to reflect like this unless it's framed as problematic. And then you have to talk to someone for your own mental health, and even that is difficult to do. It's a positive experience for me to reflect back on all of this. I hope to use this experience to shape the way I do future work. (HK, East Africa, IDPI)*

*This is the most delayed therapy, it made me think about how it's okay to be sitting with these feelings. I'm sure there are other people sitting with these feelings and have been for a long time. It's so important that spaces are held for people to come in and talk about these things. (GF, East Africa, IDPI)*

We explicitly chose a phenomenological approach



with the knowledge that IDPIs and GWEs might cause participants to “feel discomfort, anxiety, false hope, superficiality, guilt, self-doubt, irresponsibility—but also hope, increased awareness, moral stimulation, insight, a sense of liberation, a certain thoughtfulness.”<sup>44</sup> The exemplars above indicate that reflective questioning and the creation of spaces to be heard appear to be beneficial in multiple ways. As revealed by RK’s exemplar, she began to realize the ways in which she had been suppressing parts of her stories only after being given the opportunity to deeply reflect.

### *Ethics of global health education: Students as workers*

The question of who is responsible for students’ safety and well-being while participating in global public health fieldwork has not been adequately addressed. While some academics suggest that responsibility should rest with institutional review boards or research ethics boards, this would likely place the onus on the researcher (that is, the student) and relieve the university of accountability.<sup>45</sup> However, when reflecting on the ethical reasoning and need for these boards (which are designed to protect human research subjects’ rights and welfare), we must also question why similar protections have not been put in place for researchers. Do researchers not deserve the same protections as their participants? Discussions about this important consideration need to take place at both home and host institutions.

Many existing regulations and policies protect workers, such as researchers. However, students’ employment status is varied and often not protected under legislation. With the rise in global health fieldwork, we suggest that both home and host institutions should be ethically obliged to keep students healthy and well supported, just as these institutions are obligated to do for their employees. Graduate students (whether paid, unpaid, or underpaid), in essence, are workers with rights, especially when completing fieldwork. According to Bronwyn McBride et al., around “70% of unpaid and underpaid internships in the social sciences and the UN system are undertaken by young women.”<sup>46</sup> This can result

in exploitative work and highlights the issue of gender equity within this student rights issue.<sup>47</sup>

While rarely discussed, the idea of students as workers is not new. Multiple local, national, and global documents make statements or raise arguments to support this idea. In Ontario, Canada, the Occupational Health and Safety Act’s definition of worker was expanded to include students in November 2014.<sup>48</sup> Thus, the “employer has a duty to provide these unpaid workers [students] with information, instruction and supervision, and to take every precaution reasonable in the circumstances to protect their health and safety.”<sup>49</sup> With regard to the United States, Katherine Durack argues that most unpaid internships at for-profit firms are considered illegal under the US Fair Labor Standards Act. She further questions the appropriateness of the exemptions that most government agencies and nonprofit organizations receive.<sup>50</sup> Article 23 of the Universal Declaration of Human Rights states that “everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment” and that “everyone, without any discrimination, has the right to equal pay for equal work.”<sup>51</sup> McBride et al. also point out that the “routine devaluing of women’s labour promotes the feminisation of poverty, and undermines progress towards Sustainable Development Goal (SDG) 5 on gender equality and SDG 8 on decent work and economic growth.”<sup>52</sup> While academic institutions have identified ethics training as core to global health education, most do not have robust policies or procedures for protecting students’ health and safety.<sup>53</sup> By considering students as workers, universities could apply an occupational health and safety framework to support and protect students during global health practice.

### *Resonance and rigor*

Rigorous phenomenological research is aligned with empathy and humility, two components of global health ethics, which can also intersect with gender. Effective phenomenological writing occurs when the reader finds the story to be plausible, to be something she feels she could vicariously experience, or to be related to something she has ex-



perienced, while also capturing study participants' realities.<sup>54</sup> This is known as the "phenomenological nod," or imagining one's self in another's shoes.<sup>55</sup> This concept is analogous to Sarah Tracy's idea of "resonance," aimed at achieving excellent qualitative research through the "ability to meaningfully reverberate and affect an audience."<sup>56</sup> Our research study aims to offer the reader a new way to describe, conceive of, and respond to individual experiences. These new structures of meaning permit critical and vital questions to arise through empathizing and sharing stories, which can be expressed or withheld, along gendered lines. By giving voice to the lived experience of women graduate students, this study presents academic public health institutions with the opportunity to better recognize, validate, respond to, and support students and practitioners participating in global public health practice.

### *Limitations and strengths*

While some phenomenological critics argue that "the appeal to emotions and anecdote is an illegitimate philosophical move," we would agree with Havi Carel that "emotion and anecdote are fundamental building blocks of human experience."<sup>57</sup> In this study, we sought to elicit an emotional and empathetic response from the reader. While a possible limitation, we view it as an inherent strength that allows for an understanding of fluidity, ambiguity, relationality, and situational and dynamic research processes.

One study limitation is that our chosen phenomenon, global health practice, is a vast and complex topic involving a range of people, places, and institutions. While our research offers insights into this phenomenon as experienced by our participants, it does not offer deeply detailed understandings of just one type of experience (for example, the student experience of their institution's role in global public health practice, or the experience of sexual assault). Since global public health practice had yet to be explored, we chose to focus on the topic as a whole in the hope that future research will address compelling findings from our study. Due to financial and time constraints, we intentionally limited our

population group in order to have deeper and richer reflections. The amount of data collected, however, far surpasses a singular verbatim transcript, and the creation of the GWE allowed us to capture additional participants' voices.

We also recognize that participants may not fully feel that they are co-creators or collaborators. This is especially true for participants with sensitive and distressing stories, those who are still embedded in their trauma, and those who have distanced themselves altogether from global health. While participants were actively engaged in data creation, we acknowledge that we wield power in decisions regarding the research process (for example, picking study objectives and attending to some stories and not others) and that we may have missed significant data. Our reflexive practice throughout this rigorous phenomenological project was critical.

### Conclusion

This study is the first of its kind, adding a valuable contribution to the literature through a fuller understanding of global public health practice. Initial recruitment led to almost 50 responses in fewer than two weeks. The response and data generated indicate that women want to share their stories. However, as research demonstrates, women need to feel that they have a safe environment in which to do so. Our research allows for deeper understanding and meaning-making, with the hope that future researchers will continue to explore this phenomenon from multiple perspectives.

Further examination of our findings reveals a crucial need to better understand the lived experiences of oppressed groups (for example, LGBTQ individuals, gender non-conforming individuals, persons with disabilities or chronic or episodic health conditions, and racially marginalized minorities), undergraduate and international students, and students living outside the United States and Canada. Research on the experience of faculty (precarious and tenured), other staff, and postdoctoral workers also needs exploration in order to make effective, holistic, and supportive institutional changes. Further methodological

research, such as institutional ethnography, can explore the effects of intersectionality, power, and privilege on actors at home universities and host institutions. More explicit theoretical frameworks need to focus on further understanding gendered and racialized dynamics of global health practice. As illustrated, phenomenology gives voice and space to other ways of knowing and brings attention to silences or taken-for-granted experiences. The consideration of who is responsible for women graduate students' health and well-being in global public health practice is a critical student rights and gender equity issue. As a result, academic institutions need to consider their ethical duty of care to students, treat them as workers with rights, and offer better support through appropriate and accessible resources, safe spaces and time for processing experiences, and more authentic and open conversations throughout the research process.

## References

1. A. I. Matheson, J. Pfeiffer, J. L. Walson, and K. Holmes, "Sustainability and growth of university global health programs" (2014). Available at <http://csis.org/publication/sustainability-and-growth-university-global-health-programs>.
2. C. McAuliffe, R. Upshur, D. W. Sellen, and E. Di Ruggiero, "Critical reflections on mental well-being for post-secondary students participating in the field of global health," *International Journal of Mental Health and Addiction* (2018), pp. 1-13.
3. Ibid.
4. Ibid. See, for example, A. Pollard, "Field of screams: Difficulty and ethnographic fieldwork," *Anthropology Matters* 11/2 (2009), pp. 1-23; J. Paulson, N. Hopwood, L. McAlpine, and D. Mills, "Untold doctoral experiences: Research findings and recommendations from a study into the challenges of doctoral study," *Studies in Higher Education* 37/6 (2009), pp. 667-681.
5. See, for example, E. Sohn, "Health and safety: Danger zone," *Nature* 541/7636 (2017), pp. 247-249; M. Surya, D. Jaff, B. Stilwell, and J. Schubert, "The importance of mental well-being for health professionals during complex emergencies: It is time we take it seriously," *Global Health: Science and Practice* 5/2 (2017), pp. 188-196.
6. B. McBride, S. Mitra, V. Kondo, et al., "Unpaid labour, #MeToo, and young women in global health," *Lancet* 391 (2018) pp. 2192-2193; K. Ross, "'No sir, she was not a fool in the field': Gendered risks and sexual violence in immersed cross-cultural fieldwork," *Professional Geographer* 67/2 (2015), pp. 180-186; V. Ridde, C. Dagenais, and I. Daigneault, "It's time to address sexual violence in academic global health," *BMJ Global Health* (2019), pp. 1-4.
7. McBride et al. (see note 6).
8. B. La Brack and L. Bathurst, "Anthropology, intercultural communication, and study abroad," in M. Van de Berg, R. Paige, and L. Hemmings (eds), *Student learning abroad: What our students are learning, what they're not, and what we can do about it* (Sterling, VA: Stylus, 2012), pp. 188-214.
9. McAuliffe et al. (see note 2); Paulson et al. (see note 4); Pollard (see note 4).
10. Pollard (see note 4), p. 18.
11. Ibid., p. 15.
12. See, for example, Pollard (see note 4); S. T. Kloß, "Sexual(ized) harassment and ethnographic fieldwork: A silenced aspect of social research" *Ethnography* 18/3 (2016), pp. 396-414; V. Congdon, "The 'lone female researcher': Isolation and safety upon arrival in the field," *Journal of the Anthropological Society of Oxford* 7/1 (2015), pp. 15-24.
13. Ridde et al. (see note 6).
14. McAuliffe et al. (see note 2).
15. McBride et al. (see note 6).
16. Ridde et al. (see note 6), p. 1. See, for example, E. Moreno, "Rape in the field, reflections for a survivor," in D. Kulick and M. Wilson (eds), *Taboo: Sex, identity, and erotic subjectivity in anthropological fieldwork* (London: Routledge, 1995), pp. 169-189; G. Sharp and E. Kremer, "The safety dance: Confronting harassment, intimidation, and violence in the field," *Sociological Methodology* 36/1 (2006), pp. 317-327; K. Ross, "'No sir, she was not a fool in the field': Gendered risks and sexual violence in immersed cross-cultural fieldwork," *Professional Geographer* 67/2 (2015), pp. 180-186.
17. Center for Global Health, *Women in global health research initiative*. Available at <https://www.womenglobalhealth.com/about-us>.
18. K. B. Clancy, R. G. Nelson, J. N. Rutherford, and K. Hinde, "Survey of academic field experiences (SAFE): Trainees report harassment and assault," *PLoS One* 9/7 (2014), cited in McAuliffe et al. (see note 2), p. 7.
19. A. Fairchild, L. Holyfield, and C. Byington, "National Academies of Sciences, Engineering, and Medicine report on sexual harassment: Making the case for fundamental institutional change," *JAMA: Journal of the American Medical Association* 320/9 (2018), pp. 873-874; H. McLaughlin, C. Ugen, and A. Blackstone, "The economic and career effects of sexual harassment on working women," *Gender and Society* 31/3 (2017), pp. 333-358; Ridde et al. (see note 6).
20. McLaughlin et al. (see note 19), p. 352.
21. Kloß (see note 12); McAuliffe et al. (see note 2); Moreno (see note 16).
22. M. van Manen, "Phenomenology of practice," *Phenomenology and Practice* 1/1 (2007), pp. 11-30; M. van Manen, *Phenomenology of practice: Meaning-giving methods*

- in phenomenological research and writing* (New York: Routledge, 2014).
23. M. van Manen, *Researching lived experiences* (London: State University of New York Press, 1990).
  24. J. D. Crist and C. A. Tanner, "Interpretation/analysis methods in hermeneutic interpretive phenomenology," *Nursing Research* 52/3 (2003), p. 202.
  25. Ibid.
  26. H. Carel, *Illness: The cry of the flesh* (Stocksfield: Acumen, 2013).
  27. M. A. van Manen, "Phenomenology of Practice" (workshop at the 23rd Annual Qualitative Health Research Conference, Quebec City, Canada, October 16, 2017).
  28. van Manen (2014, see note 22); Carel (2013, see note 26).
  29. L. Finlay, "'Outing' the researcher: The provenance, process, and practice of reflexivity," *Qualitative Health Research* 12/4 (2002), p. 531.
  30. van Manen (2014, see note 22).
  31. L. Finlay, "Engaging phenomenological analysis," *Qualitative Research in Psychology* 11/2 (2014), p. 121.
  32. Ibid., p. 135.
  33. M. van Manen. *"Doing" phenomenological research and writing: An introduction* (Edmonton: University of Alberta, 1984), p. 21.
  34. Crist and Tanner (see note 24), p. 204.
  35. S. Crowther, P. Ironside, D. Spence, and L. Smythe, "Crafting stories in hermeneutic phenomenology research: A methodological device," *Qualitative Health Research* 27/6 (2017), pp. 826–835.
  36. Finlay (2014, see note 31).
  37. van Manen (1990, see note 23).
  38. J. Shaw and D. Connelly, "Phenomenology and physiotherapy: Meaning in research and practice," *Physical Therapy Reviews* 17/6 (2012), pp. 398–408.
  39. Crowther et al. (see note 35); K. Lopez and D. Willis, "Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge," *Qualitative Health Research* 14/5 (2004), pp. 726–735.
  40. M. Merleau-Ponty, *Phenomenology of perception* (London: Routledge, 2013); van Manen (2014, see note 22).
  41. McAuliffe et al. (see note 2).
  42. Ibid.
  43. S. Delamont, "Familiar screams: A brief comment on 'Field of Screams,'" *Anthropology Matters* 11/2 (2009), p. 1.
  44. van Manen (1990, see note 23), p. 162.
  45. D. Dominey-Howes, "Seeing 'the dark passenger': Reflections on the emotional trauma of conducting post-disaster research," *Emotion, Space and Society* 17 (2015), pp. 55–62.
  46. McBride et al. (see note 6), p. 2192.
  47. Ibid.
  48. *Occupational Health and Safety Act*, Ontario, Canada, Bill 18 (2014). Available at <https://www.ola.org/en/legislative-business/bills/parliament-41/session-1/bill-18>.
  49. Ontario Ministry of Labour, *FAQs: Definition of "worker" in the Occupational Health and Safety Act* (2015). Available at <https://www.labour.gov.on.ca/english/hs/faqs/worker.php>.
  50. K. Durack, "Sweating employment: Ethical and legal issues with unpaid student internships," *College Composition and Communication* (2013), p. 246.
  51. Universal Declaration of Human Rights, G.A. Res. 217A (III) (1948), art. 23.
  52. McBride et al. (see note 6), p. 2192.
  53. A. D. Pinto and R. E. Upshur, "Global health ethics for students," *Developing World Bioethics* 9/1 (2009), pp. 1–10; K. A. Stewart, "Teaching corner: The prospective case study," *Journal of Bioethical Inquiry* 12/1 (2015), pp. 57–61.
  54. B. Raingruber and M. Kent, "Attending to embodied responses: A way to identify practice-based and human meanings associated with secondary trauma," *Qualitative Health Research* 13/4 (2003), pp. 449–468; van Manen (2014, see note 22).
  55. van Manen (1990, see note 23).
  56. S. Tracy, "Qualitative quality: Eight 'big-tent' criteria for excellent qualitative research," *Qualitative Inquiry* 16/10 (2010), p. 844.
  57. H. Carel, *The phenomenology of illness* (Oxford University Press, 2016), p. 7.



## COMMENTARY

# Where There Is No Hashtag: Considering Gender-Based Violence in Global Health Fieldwork in the Time of #MeToo

RACHEL HALL-CLIFFORD

In global health, we prioritize work where there is no doctor—often in remote and sometimes dangerous places—and certainly where there is no #MeToo hashtag, no groundswell of activism to support women’s rights. In such contexts, women in the field face distinct challenges. Through sharing my own experiences, I hope to encourage open dialogue and action to address gender-based violence within global health.

## Gender-based violence in an evidence-based field

Global health aspires to be evidence-based, yet a lack of data on gender-based violence among fieldworkers hinders our ability to address it comprehensively within our institutions and protocols. Here, I offer two personal fieldwork experiences as small data points of this vast but unmeasured phenomenon. My experiences are limited and privileged by virtue of my education, ethnicity, and status as a foreigner in the Guatemalan field site where I have worked for nearly 15 years. So many women contribute to global health in important and varied ways—as community partners, local staff, and international researchers and facilitators—but I can only speak to my own experiences in hopes that others will add theirs. I acknowledge that sharing details of sexual assault can re-inscribe a narrative of women as sexual objects, but I believe we must not obscure the “hard facts of corporeality” in fieldwork.<sup>1</sup>

This first incident took place when I was a doctoral student, and the second occurred nearly ten years later when I was working as a principal investigator on a large research grant.

*Soon after moving in with a Guatemalan family in an urban area, it became clear that I would have to arrange research activities and outings during daylight hours. They warned me that the streets were not safe after dark, and that I should not be seen out at night. Months later, I was walking home in the early evening with the daughter of the household, married and in her mid-20s like myself at the time, after an afternoon spent running errands together and chatting with other neighborhood women. We sped up to get past men gathered outside the small shop on the corner of our street. It was not my first encounter with men on street corners, who often catcalled me as I passed in the daytime: “hello, Barbie” and “come here, baby.” My body had learned the geography of the street,*

---

RACHEL HALL-CLIFFORD, MPH, MSc, PhD, is assistant professor of Anthropology and Public Health at Agnes Scott College in Decatur, Georgia, USA, and Director of the NAPA-OT Field School in Guatemala.

Please address correspondence to Rachel Hall-Clifford. Email: rhallclifford@agnesscott.edu.

Competing interests: None declared.

Copyright © 2019 Hall-Clifford. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted noncommercial use, distribution, and reproduction in any medium, provided the original author and source are credited.



*and I hunched my shoulders and lowered my gaze reflexively as we approached. This time, the group was emboldened by numbers and beer, the empty cans marking ownership of the street as clearly as traffic cones.*

*The heavy metal door to our house came into sight as my friend and I rounded the corner, with gazes, words, and whistles raining over us. A tug on the blue nylon of my raincoat, and I was suddenly off the street, pulled through a creaking piece of sheet metal into the disorienting dark of a quiet alley. I heard the footsteps of my friend running home as I felt hands pushing my shoulders down against a cinderblock wall, followed by the sound of a zipper. I was on the ground looking at a dog bowl half-filled with water in the dirt. My nose filled with the sour smell of second-hand alcohol, and a man's voice said, "I'll show you, bitch." ... When I realized we were alone and that my attacker was very drunk, I pushed, twisted, and pulled away, aided by the loose slickness of my raincoat.*

*I pushed back out into the glare of the street and ran home, where my friend was waiting inside the door. Just as the pit of fear in my stomach had time to bloom outward and rubberize my limbs, my friend cautioned me not to say anything to others in the house. Everyone would only think less of me. Anyway, she was the object of the men's attention before I arrived, so I should not get ideas about being special. I was confused by her response, expecting to bond in outrage, and ashamed by what felt like a failure to navigate an obvious fieldwork risk, despite all of my efforts to avoid it.*

I published a partial account of this incident soon after returning to Boston following my doctoral fieldwork.<sup>2</sup> Co-authored with a dear friend and classmate who heroically escaped from kidnappers in Syria, the short piece fulfilled in some small way our mutual feelings of obligation to share our experiences of gender-based assault with colleagues and future fieldworkers, particularly as we had struggled to connect our experiences to existing fieldwork literature. (Afterward, however, neither of us included the experiences reported in the article in our dissertations. We just did not see them as "data.") I did not discuss this experience with my graduate school advisors at the time. I now recognize how much I value(d) my persona as a successful fieldworker, "tough" and "self-sufficient." The image of me as weak and vulnerable,

literally brought to my knees because of my gender, felt like something to keep to myself.

## Embodied inequality

Fieldwork happens through the movement, interaction, and labor of human bodies—it is an exercise in embodiment. Fieldworkers' bodies and identities are often objects of scrutiny within the communities in which they work, particularly as they may defy or confound local taxa.<sup>3</sup> Women, both local and foreign, must navigate gender norms in the field while sometimes purposefully deviating from them to achieve project goals. Women in the field sometimes gain "honorary male" status, meaning they can (partially) transcend local gender norms.<sup>4</sup> Perhaps most importantly for fieldwork, women are often able to circumvent local public/private dichotomies that establish which genders can be in particular spaces at particular times. Yet in doing so, they also further become dangerous "matter out of place," which symbolic anthropologist Mary Douglas has notably posited as the very definition of dirt.<sup>5</sup> While "out of place" women can potentially claim greater freedom of movement than local women, they may also be subject to disdain, social censure, and mistreatment because of it. This duality of privilege and susceptibility is central to the embodied experience of fieldwork for women.

I am often amused when Guatemalan friends and colleagues point out that I dress like a man in my loose pants and button-down shirts, sometimes providing fodder for good-natured jokes and offers of more appealing clothing. Other women conducting fieldwork in Guatemala have reported similar experiences.<sup>6</sup> During a walk through a bad neighborhood at dusk, a male Guatemalan colleague once laughed and said I was physically intimidating—meaning it seemed I could handle an attack. As a short, small-framed woman, I was a bit proud of this acknowledgment of my honorary male status and joked back that I would protect him. I took his comment to mean I was doing something right and that I had adapted to my research context. At the time, I did not question what that said about gender norms and violence in my research site or prob-

lematize my tacit aspiration to best them. However, in this second experience of gender-based violence, I was reminded of the limitations of my ability to transgress local gender norms during fieldwork.

*During a recent implementation project, I drove out to a rural Guatemalan community on a short visit to local project participants. I was very friendly by then with one woman who was a community leader, and she and I had planned for me to stay overnight in her family's home. When I arrived, it seemed prudent for her husband to lock my shiny rental car from the airport into a carport structure at the base of the steep hill to their home, removing it from public sight. We spent a friendly evening in the kitchen cooking and chatting with their kids, and I excused myself to my bedroom (borrowed from the couple's older children) soon after dinner, not wanting to intrude further on family routines. I organized some paperwork and data entry and fell asleep. Not long after midnight, I awoke to hear a key unlocking my door from the outside. My door wedge blocked easy opening of the door, and I heard my friend's husband muttering at the unexpected obstruction. I jumped up from the bed and prepared for a physical confrontation that thankfully never happened. I heard him move away and softly shut the door to his own bedroom.*

*I spent the rest of the night awake in the dark, my mind scrolling endlessly through lists of possible people to call for help and strategies for leaving safely. In the end, I waited until I heard the familiar sounds of tortillas being made for breakfast and emerged from the room. I greeted my friend, backpack already over my shoulder, saying I needed her to unlock the carport because I had an early meeting. She obliged in leading me down the slope to the car, but the warmth and ease of the previous evening and our friendship were gone. More than anything, I wanted to apologize to her as she stood watching me drive away.*

## The symbolic violence of fieldwork

When I first shared my experiences of gender-based violence on fieldwork within a professional context last year, a well-meaning colleague asked why I did not avoid the street corner where my attacker grabbed me. (It was the only way home. And there was always a corner to be avoided, no matter the variation in route.) Another asked what kind of door

wedge I used. (Soft rubber seems to work best.) But these questions seemed to indicate a larger point getting lost. My technique and skill as a fieldworker was being questioned in light of gender-based violence—not our paradigms of conducting fieldwork or assessing its successful completion. Nell Gluckman's recent article on the fate of Henrietta Schmerler, an anthropology graduate student who was raped and murdered on fieldwork in 1931, illustrates how women have long been blamed for their own experiences of gender-based violence in the field regardless of their competence—the professional equivalent of “what was she wearing?”<sup>7</sup> That women in the field will be assaulted is taken as the natural “order of things,” unquestioned and largely unseen, in global health—fulfilling the archetype of symbolic violence in the sense that we fail to recognize it as such.

Within a system of symbolic violence, inequalities are taken to be inherent and immutable, and they remain unquestioned by either perpetrators or victims.<sup>8</sup> Hence, victims of symbolic violence are complicit through their perpetuation of the system of violence, however unwitting it might be. I have taken on the machismo attitude that I am a tough and resilient fieldworker—failing to see how this contributes to a patriarchal system that keeps human moments of fear and weakness hidden away. I limit opportunities for helping other women and creating shared recognition of common experiences. Moreover, the privileges of “honorary male” status have profound limitations. After each of the experiences described above, my relationships with local women were damaged, irrevocably in the second case. I felt my culpability as an outsider deeply, having unwittingly upset a fragile local equilibrium; this is the antithesis of the solidarity with communities that fieldwork seeks to build.

## Women's rights and the promotion of health as a human right

Much work has been done in recent years to ensure that women's rights are viewed as human rights. The Convention on the Elimination of All Forms of Discrimination Against Women, adopted in

1980, did not explicitly address violence as a form of discrimination against women.<sup>9</sup> In 2017, the Committee on the Elimination of Discrimination Against Women issued an updated General Recommendation that acknowledges widespread violence against women as both a human rights violation in itself, as well as inhibitory to the enjoyment of other fundamental human rights, including: “the right to life, health, liberty and security of the person, the right to equality and equal protection within the family, freedom from torture, cruel, inhumane or degrading treatment, freedom of expression, movement, participation, assembly and association.”<sup>10</sup> This more expansive positioning of the reality of violence against women within human rights frameworks is important, but it points to a significant challenge for global health. This is a field dedicated to the promotion of health as a human right, but we fall short in ensuring that right to women in global health as we fail to adequately address gender-based violence in the field.

There are many barriers to reporting gender-based violence in global health fieldwork. Women who experience it may be disempowered to do so by virtue of their geography or organizational position within the complex power dynamics of global health. Perhaps above all, global health is populated by workers who want to improve the world—to push forward in making the right to health a reality—and it can be difficult to include one’s own rights as a fieldworker alongside our focus on the rights of communities in which we work. I am very aware that, in the end, my female Guatemalan friends stay, and I go. They live in places where there are no hashtags, where there is no #MeToo, and no functional reporting procedures or formal support systems to counteract gender-based violence. We must ensure that gender equity is for everyone, regardless of their position, power, or role in global health.

## Acknowledgments

Thank you to Beth Hackett, Gelya Frank, Martha Rees, David Addiss, Bob Cook-Deegan, and Jim Lavery for comments and encouragement on this

topic. Thank you to Louise Lamphere for her comments on this work as a panel discussant at the 2019 Society for Applied Anthropology meetings.

## References

1. D. Zarkov and K. Davis, “Ambiguities and dilemmas around #MeToo: how long and where to?” *European Journal of Women’s Studies* 25/1 (2018), pp. 3-9.
2. L. Gifford and R. Hall-Clifford, “From catcalls to kidnapping: Towards an open dialogue on the fieldwork experiences of graduate women,” *Anthropology News* 49/6 (2008), pp. 26-27.
3. J. Okely, “Fieldwork embodied,” *The Sociological Review* 55 (2007), pp. 65-79.
4. R. Behar, *The vulnerable observer: Anthropology that breaks your heart* (Boston: Beacon Press, 2014).
5. M. Douglas, *Purity and danger: An analysis of concepts of pollution and taboo* (New York: Routledge, 2003).
6. D.M. Nelson, *Who counts? The mathematics of death and life after genocide*. (Durham, NC: Duke University Press, 2015).
7. N. Gluckman, “How Henrietta Schermer was lost, then found,” *Chronicle of Higher Education* (October 2018).
8. P. Bourdieu and L. Wacquant, “Symbolic violence,” in N. Scheper-Hughes and P. Bourgois (eds), *Violence in war and peace* (Oxford: Blackwell, 2004).
9. C. Bunch, “Transforming human rights from a feminist perspective,” in J. Peters and A. Wolper (eds), *Women’s rights, human rights: international feminist perspectives* (New York: Routledge, 1995), pp. 11-17.
10. CEDAW, General Recommendation No. 35 on gender-based violence against women, updating General Recommendation No. 19 (2017). Available at [https://tbinternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/1\\_Global/CEDAW\\_C\\_GC\\_35\\_8267\\_E.pdf](https://tbinternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/1_Global/CEDAW_C_GC_35_8267_E.pdf).

## COMMENTARY

# #MeToo Meets Global Health: A Call to Action

A STATEMENT BY PARTICIPANTS OF THE GLOBAL HEALTH FIELDWORK ETHICS  
WORKSHOP, APRIL 2018

*This statement arose from discussions during the Global Health Fieldwork Ethics Workshop held in Atlanta, Georgia, USA in April 2018, co-sponsored by Agnes Scott College, The Taskforce for Global Health, and Emory University Rollins School of Public Health. As participants from a wide range of academic and global health implementation organizations discussed ethics challenges in fieldwork settings, it became clear that gender-based violence was an issue of vast importance that has not been adequately considered for global health fieldworkers and participants. This statement highlights key themes on gender-based violence that emerged from our discussions and calls for further action.*

In many respects, global health is a women-centered enterprise. Women are often the local participants in global health programming, are growing in numbers as members of local implementation staff, and form a clear majority in the classrooms of public health educational institutions. Despite this deep engagement, women in global health—as in workplaces, fields of study, and societies across the globe—are not positioned as equals. Of course not. Gender bias shapes our norms and expectations for success and who will achieve it in global health, even as we fight collectively for equity in access to health care and other human rights issues around the globe. Further, as the #MeToo movement has begun to lay bare across employment sectors in the US and beyond, women in global health also experience sexual harassment, sexual assault, and other forms of gender-based violence, about which they are encouraged by institutional structures and processes to remain silent. For this culture of silence, we—the men, the women, the *people*, of global health—are all responsible. Gender-based violence in global health is not a women's issue. It is an issue for all of us.

In this statement, we call for increased attention to sexual harassment, sexual assault, and gender-based violence of all forms across global health, from our training programs to research institutions to implementation organizations. Women and people of all gender identities and expressions have the right to safe workplaces, and we have the right to be acknowledged without judgement when our safety has been compromised.<sup>1</sup> We call particular attention to women in contexts of “fieldwork,” where local norms may conflict with global health goals and operational practices. Though we choose inclusivity through use of the term “gender-based violence,” we foreground violence against women and the more subtle forms of discrimination women disproportionately experience.<sup>2</sup> Our goals are to recognize the legacies and structures in global health that enable gender-based violence, highlight some of the challenges to women's equality and safety in global health fieldwork, and point to steps forward in creating healthy work environments for all. Above all, we wish to encourage open dialogue and action to address gender-based violence within global health, where such violence has been an object of study but rarely an acknowledged reality for many who work in the field.



## Gendered experiences of global health

While the paternalism of the colonialist roots of global health have been acknowledged, if not removed from our theoretical and operational paradigms, we have yet to fully reconcile how these antecedents to our contemporary work have shaped gender norms and biases within our field.<sup>3</sup> The challenges particular to women go largely unacknowledged in the formal discourse of global health. Gender-based violence has become a vital area of global health study and programming in recognition of the terrible prevalence of gender-based violence; indeed, we know that 35% of the world's women experience gender-based violence in their lifetimes.<sup>4</sup> The United Nations has developed protocols for mitigating gender-based violence in contexts of humanitarian crises because of the increased vulnerability of women and girls for sexual violence and exploitation in these settings.<sup>5</sup> The increased attention on the global health burden of gender-based violence over the past 30 years is an important and encouraging step toward health equity.<sup>6</sup> However, the women who participate in global health—the program managers, fieldworkers, researchers, local promoters, and community members—have not been appropriately acknowledged as susceptible to gender-based violence, potentially made more so through their global health engagement.

Within the university settings in which global health workers are trained in high-income countries, the large proportion of women enrolled as students (one leading institution reports up to 85% of undergraduate and 70% of graduate students interested in global health are women) would seem to indicate that these are no longer male-dominated spaces.<sup>7</sup> However, we also see that women face greater challenges in attaining permanent academic positions, moving up the ranks of the academic hierarchy, and having their professional achievements recognized.<sup>8</sup> In recent studies, women from across academic disciplines have described high rates of sexual harassment, discrimination, and assault. Among women in academic institutions, more than 50% of faculty and staff, and between 20% and 50% of students, report experiences of

sexual harassment, impacting their professional, psychological, and physical health. This harassment is most likely to occur when women are trainees.<sup>9</sup> Beyond the experience of sexual harassment, women in academic contexts are far more likely than men to report experiences of gender bias in academic settings and in professional advancement.<sup>10</sup>

Outside of the academy, women in global health face gender-based violence as they take up roles in implementation organizations, where incidents can occur both in the “field” and in “home” offices. As in academic settings, women are vastly underrepresented in global health leadership roles; only 25% of representatives in the World Health Assembly are women.<sup>11</sup> Professional environments where women are not well-represented in leadership may be more likely to perpetuate workplace cultures where sexual harassment and barriers to successful reporting and responsive action are tolerated. Within global health institutions where people from diverse cultural backgrounds are brought together, instances of sexual harassment may be brushed aside as cross-cultural misunderstandings.

Prominent media coverage of sexual abuse within the humanitarian aid sector has highlighted the reality that global health workers can also be perpetrators of gender-based violence.<sup>12</sup> Perpetrators of gender-based violence in global health and aid organizations can target women in local communities who are project recipients, as well as their colleagues.<sup>13</sup> Global health institutions have a responsibility to consider that their employees and those engaged in their projects can be both the victims and perpetrators of gender-based violence, and the institutions must be able to provide appropriate support and disciplinary action. Following recent aid sector scandals, new guidance is emerging for reporting and accountability mechanisms.<sup>14</sup>

Relationships are at the center of global health projects, and the deep power dynamics embedded within those relationships impact our successes. Gender affects the ability to command respect and build rapport within professional relationships, and when gender-based violence enters into the work of global health, that work is indisputably compromised. Many global health workers enter the field



due to a desire to “do good,” and the goal of helping others may make it more challenging for fieldworkers to report gender-based violence. When our work is to help achieve the right to health care for others, standing up for our own rights can feel antithetical to that purpose, and women may be reluctant to report instances of assault and abuse. However, the cost of helping others should not come at the hidden expense of personal health, safety, and career advancement due to gender-based violence.

### Gender-based challenges in global health fieldwork

Women everywhere face gender-based violence, but women in global health fieldwork can be particularly at risk for sexual harassment, sexual assault, and other forms of gender-based violence. We define fieldwork broadly to mean activities undertaken to further global health research or program implementation by both local and foreign global health workers. The experiences of women in global health fieldwork are incredibly varied, both in the nature of their work and in the ways that they may experience gender-based violence. Yet, there are distinct challenges that global health fieldwork poses for women. A recent survey of field experiences across academic disciplines showed that 70% of women experienced sexual harassment and 26% experienced sexual assault during fieldwork; the study further illustrated that fieldsites often lack relevant sexual harassment policies and codes of conduct that would be in place in traditional workplaces.<sup>15</sup> Experiences of rape and attempted rape have been documented as significant issues for women anthropologists.<sup>16</sup> The most substantive review of gender-based violence against public health fieldworkers was published two decades ago, and the issue of gender-based violence in global health fieldwork is vastly understudied.<sup>17</sup>

Women in global health are tacitly expected to follow fieldwork methods established by men, and women must work harder to live up to the unspoken standards of being “tough enough” to make it in the field. On top of the routine challenges of global health research or project implementation,

women fieldworkers must invest incredible energy in ensuring their personal safety through: carefully monitoring their behavior and local perceptions of it, creating a personal appearance that cannot be construed as sexually provocative, and ensuring safe housing, often by needing to live within the context (and rules) of a local family.<sup>18</sup> These tactics are context-specific, and they are more likely to be shared in the hallways outside of conference rooms rather than through training sessions held inside. Informal strategy-sharing is an important lifeline for many women in global health; for example, women regularly cut off or color their hair, wear baggy clothes, stay indoors after dark, and even wedge a rubber doorstop under their doors at night. The necessity of such (unacknowledged) steps in order to maintain safety and complete work is far more pronounced for women than for men.

Global health fieldworkers are trained to respect local norms and customs, yet adherence to those norms can shape and constrain opportunities for collecting data or implementing programs, particularly for women. Women, both local and foreign, must navigate gender norms within the fieldwork setting while sometimes explicitly flouting them to achieve global health project objectives. The disruption of gender norms inherently introduces risks for women, and foreign women are routinely particular objects of scrutiny in fieldwork settings. Though their status as foreigners may counterbalance their gender identity, affording them greater freedom and mobility than local women, women undertaking fieldwork abroad are often targets of gender-based violence. While some types of sexual harassment may be normative for the local context, it can be challenging for foreign women in the field to adjudicate what is “normal” and potentially to be ignored—some catcalls or invasions of personal space are perhaps to be expected—and what should be cause for concern, a change of strategy, or merit reporting. There is no clear line between an acceptable ordinary and an abusive extraordinary when it comes to sexual harassment and assault in a cross-cultural context. Indeed, in global health fieldwork, as in human rights, cultural relativism has limits. Women will have different personal

views of what is comfortable or acceptable during participation in global health projects, but they should not have to make decisions about balancing their safety with project completion without the support of their institutions and colleagues. Cultural difference should not be invoked as a reason to dismiss or discount the concerns and negative experiences of women in the field.

### #MeToo and implications for global health

The #MeToo movement has brought unprecedented attention to gender-based violence. #MeToo has had significant limitations in its representation of the experiences of all women and people of diverse gender identities, and it has been widely criticized for eliding the voices of women of color and prioritizing the experiences of a powerful elite.<sup>19</sup> It has, however, unquestionably moved gender-based violence into mainstream public discourse. The #MeToo movement has been highlighted as an opportunity to frame sexual harassment as a public health issue and address it more holistically within the context of health promotion.<sup>20</sup> It has not yet been meaningfully harnessed as an opportunity to improve the experiences of women in public health or global health, though emerging collectives such as Women in Global Health are encouraging. Some, but not all, of the professional organizations of disciplines contributing to global health have sexual harassment policies, and only the American Anthropological Association's policy acknowledges that sexual harassment and assault may occur during fieldwork away from home institutions.<sup>21</sup>

#MeToo has marked an important shift in how gender-based violence is reported and counteracted. For so long, women who report gender-based violence have been disregarded or discredited. The stigma of gender-based violence means that these uninvited experiences become a woman's defining identity, and their other work, achievements, and professional identities fade away.<sup>22</sup> Some of the women who have described sexual assault and rape in the field have done so under pseudonyms.<sup>23</sup> Reshma Jagsi, a clinician who has studied sexual harassment within medicine, has insightfully de-

scribed her own unconscious efforts in reputation management when she realized she was quick to make the distinction that she has studied sexual harassment but not been a victim of it.<sup>24</sup> The fear of damaged reputations and the stigma of being the object of gender-based violence are real. Women must be positioned as agents, not objects, of global health—able to take up global health roles from community participant to institutional leader without fear that their experiences will be dismissed or bar them from pursuing their goals.

### Points of entry for addressing gender-based violence in fieldwork

Gender equity is a problem in global health, and the dangers of inequity become most clear in contexts of fieldwork. While no fieldwork is without risk, and many global health fieldwork sites are dangerous and carry substantial risks, we can take important steps to mitigate risk through appropriate training and institutional support. One danger in describing the gender-based discrimination and violence that women face during fieldwork is that they will be sidelined from such work. This is not what we suggest—far from it—nor do we suggest that paternalistic decisions should be made on when, where, and how women should engage in fieldwork. Open dialogue about the risks of gender-based violence during fieldwork can be an important starting point to enable appropriate preparation, decision-making, and support for women in the field. We also need to prioritize research on this vastly underreported and understudied issue.

### *Training*

Within academic institutions, meaningful field-based training opportunities are often limited until much is at stake for a student's future career success. While there is a great deal of variation in training strategies across the disciplines contributing to global health, students are often sent into the field either alone or to work with local supervisors in unfamiliar contexts. Global health students and trainees are particularly vulnerable to gender-based violence because they may be ill-prepared for the

challenges they will encounter—in large part because those challenges often go unacknowledged in our training curricula. It is important for mentors and supervisors to raise awareness that gender-based violence can be a reality of fieldwork. Opportunities to prepare for potential challenges and develop strategies for addressing risks specific to the fieldwork context are of great value but are not uniformly available. Global health training institutions can take an important step in openly sharing training procedures, curricula, and lessons learned so that best practices can be developed across the field.

Open discussion would also dispel the notion that facing particular fieldwork challenges, including gender-based violence, undermines the legitimacy of research and the expertise of the fieldworker. Acknowledging our human susceptibilities in global health fieldwork can open new avenues for mentors and mentees, faculty and students, researchers and field implementation teams to share experiences of gender-based violence and other fieldwork challenges across gender and personal identities. The denial of susceptibilities in general and of gender-based violence in particular may stem from individual and institutional malaise that such topics are difficult to handle well, but this does not justify ignoring them. Deans of schools of public health, faculty mentors, and field supervisors must take up the responsibility to discuss gender-based violence in fieldwork and include it in their curricula for all students. Above all, attitudes and approaches that blame the victim must be removed from our peer, supervisory, and institutional relationships in global health; women can be well-prepared, do everything right, and still encounter gender-based violence.

### *Institutional support*

Global health institutions must better balance the need to maintain positive reputations with the need to acknowledge and address gender-based violence. Appropriate preparation for global health workers entering the field is essential, but ongoing support and mechanisms for reporting gender-based violence are equally important. Training needs and methods

may differ among government, non-governmental, and academic institutions, but all institutions have opportunities to devote explicit attention to the risks and challenges distinctive to women. Institutions should engage people of all genders in discussions of gender-based violence and trainings on how to recognize and report it within the specific institutional context and work setting. Institutions must also comply with legal responsibilities to students, employees, and clients and any liability they may incur through these relationships; yet legal obligations cannot serve as a proxy for an institutional commitment to equality. Some legal structures, such as Title IX for US higher education institutions, may prescribe protections for women but create limitations for individual decisions about disclosures of gender-based violence and options for institutional support. Institutions, therefore, should consider how to go beyond legal obligations to promote gender equality within their particular mission. They must work to disentangle the complex webs of organizational values, power, and gender that keep women sidelined from leadership roles. As the vanguard of the right to health, our field has the opportunity to lead a sea change in creating equitable and healthy working environments.

### Conclusion: Only the beginning

We call for an inclusive #MeTooGlobalHealth—not a moment, not a movement, but the *modus operandi* of global health. Simply, we should respect the contributions and experiences of all our colleagues and participants, and we must elevate gender-based violence until equity is no longer a sentiment but a reality. Words, no matter how strongly felt, cannot fix gender-based violence in global health workplaces, but our collective action can. We hope to create space within global health for others to speak for themselves and be acknowledged in solidarity and support. We believe in building action rooted in our shared experiences to improve prevention, recognition, and responses to gender-based violence in global health.<sup>25</sup> Global health must apportion some of our emphases on equity and the rights to health and safe living and working conditions to

ourselves, ensuring that these rights are attainable for those engaged in global health work, too.

We have committed to acknowledging and addressing gender-based violence in global health. We assert that gender equity is for everyone—and we should all contribute. To join us in solidarity with this statement, share resources and specific points for action, and add to the conversation, please visit: [wetooglobalhealth.org](http://wetooglobalhealth.org).

Rachel Hall-Clifford, Agnes Scott College  
David Addiss, The Task Force for Global Health  
Peter Brown, Emory University  
Arachu Castro, Tulane University  
Mary Clisbee, Zanmi Lasante and  
Partners in Health  
Robert Cook-Deegan, Arizona State University  
Dabney P. Evans, Emory University  
Arlan Fuller, Harvard University  
Aubrey Graham, Emory University  
Michelle Grek, Emory University  
Deirdre Guthrie, University of Notre Dame  
Olusimbo Ige, United Methodist Committee  
on Relief  
Arthur Kleinman, Harvard University  
Stephanie Larson, Emory University  
James Lavery, Emory University  
Deborah McFarland, Emory University  
Dave Ross, The Task Force for Global Health  
Adam Weiss, The Carter Center  
Breanna Wodnik, Emory University  
Christopher Woods, Duke University

## References

1. UN General Assembly, *Convention on the Elimination of All Forms of Discrimination Against Women*, United Nations, Treaty Series (1979), vol. 1249, p. 13. Available at <http://www.refworld.org/docid/3ae6b3970.html>.
2. Coalition of Feminists for Social Change (COFEM), “Why does GBV programming focus on women and girls? Feminist Pocketbook Tip Sheet 2” (2018). Available at <https://cofemsocialchange.org/wp-content/uploads/2018/11/TS2-Why-does-GBV-programming-focus-on-women-and-girls.pdf>.
3. R.M. Packard, *A history of global health: interventions into the lives of other peoples* (Baltimore, MD: JHU Press, 2016).
4. C. García-Moreno, C. Pallitto, K. Devries, H. Stöckl, C. Watts, and N. Abrahams, *Global and regional estimates of violence against women: prevalence and health effects of intimate partner violence and non-partner sexual violence* (World Health Organization, 2013).
5. Inter-Agency Standing Committee, “Guidelines for Gender-Based Violence Interventions in Humanitarian Settings: Focusing on Prevention of and Response to Sexual Violence in Emergencies,” in *Guidelines for Gender-Based Violence Interventions in Humanitarian Settings: Focusing on Prevention of and Response to Sexual Violence in Emergencies*, (2005).
6. L. Heise, *Violence against women: The hidden health burden* (WHO: World Health Statistics Quarterly, 1993) 46/1, pp. 78-85; L. Heise, M. Ellsberg, and M. Gottmoeller, “A global overview of gender-based violence,” *International Journal of Gynecology & Obstetrics* 78 Suppl. 1 (2002).
7. J.A. Downs, M.L.K. Reif, A. Hokororo, and D.W. Fitzgerald, “Increasing women in leadership in global health,” *Academic medicine: Journal of the Association of American Medical Colleges* 89/8 (2014), pp.1103-1107.
8. R. Morgan, R. Dhatt, K. Muraya, K. Buse, and A.S. George, “Recognition matters: Only one in ten awards given to women,” *The Lancet* 389/10088 (2017), pp. 2443-2586.
9. K.B. Clancy, R.G. Nelson, J.N. Rutherford, and K. Hinde, “Survey of academic field experiences (SAFE): Trainees report harassment and assault,” *PLoS One* 9/7 (2014), p.e102172; National Academies of Sciences, Engineering, and Medicine, *Sexual harassment of women: climate, culture, and consequences in academic sciences, engineering, and medicine* (Washington, D.C.: National Academies Press, 2018).
10. R. Jagsi, K.A. Griffith, R. Jones, C.R. Perumalswami, P. Ubel, and A. Stewart, “Sexual harassment and discrimination experiences of academic medical faculty,” *JAMA* 315/19 (2016), pp. 2120-2121.
11. Z. Talib and M. Barry, “Women leaders in global health,” *The Lancet Global Health* 5/6 (2017), pp. e565-e566.
12. C. Powell and M. Moncino, “#MeToo hits the humanitarian aid sector: Time to close the accountability gap,” *Council on Foreign Relations* (March 2018). Available at <https://www.cfr.org/blog/metoo-hits-humanitarian-aid-sector-time-close-accountability-gap>.
13. N. Einbinder, *Amid Allegations of Abuse, Aid Workers Describe Culture of Sexual Misconduct* (August 2018). Available at <https://www.pbs.org/wgbh/frontline/article/amid-allegations-of-abuse-aid-workers-describe-culture-of-sexual-misconduct/>.
14. Oxfam, *Safeguarding in action: Our 10-point plan* (February 2018). Available at <https://www.oxfam.org/en/oxfams-commitment-stamping-out-sexual-harassment-and-abuse> UK Parliament, *Sexual exploitation and abuse in the aid sector* (July 2018). Available at <https://publications.parliament.uk/pa/cm201719/cmselect/cmintdev/840/84002.htm>.

15. Clancy et al. (see note 9).
16. N. Howell, "Surviving Fieldwork: A Report of the Advisory Panel on Health and Safety in Fieldwork," *American Anthropological Association Special Publication* No. 26. Linda A. Bennett, series ed. (Washington, DC: American Anthropological Association, 1990).
17. J.M. Schulte, B. J. Nolt, R. L. Williams, C. L., Spinks, and J.J. Hellsten, "Violence and threats of violence experienced by public health field-workers," *JAMA* 280/5 (1998), pp. 439-442.
18. C. McAuliffe, R. Upshur, D.W. Sellen, and E. Di Ruggiero, "Critical reflections on mental well-being for post-secondary students participating in the field of global health," *International Journal of Mental Health and Addiction* (2018), pp.1-13.
19. H. Kearl, *The Facts Behind the #MeToo Movement: A National Study on Sexual Harassment and Assault* (Reston, Virginia: Stop Street Harassment, 2018). Available at <http://www.stopstreetharassment.org/wp-content/uploads/2018/01/Full-Report-2018-National-Study-on-Sexual-Harassment-and-Assault.pdf>.
20. A. O'Neil, V. Sojo, B. Fileborn, A.J. Scovelle, and A. Milner, "The #MeToo movement: an opportunity in public health?" *The Lancet* 391/10140 (2018), pp. 2587-2589.
21. American Anthropological Association. *American Anthropological Association's Policy on Sexual Harassment and Sexual Assault* (2018). Available at <https://www.americananthro.org/LearnAndTeach/Content.aspx?ItemNumber=22956&navItemNumber=22957>. American Medical Association. *Sexual Harassment in the Practice of Medicine*. Available at <https://www.ama-assn.org/delivering-care/sexual-harassment-practice-medicine>.
22. E. Goffman, *Stigma: Notes on the management of spoiled identity* (Englewood Cliffs, NJ: Spectrum, 1963).
23. C. Winkler, *One night: Realities of rape* (Walnut Creek, CA: Rowman Altamira Press, 2002).
24. R. Jagsi, "Sexual harassment in medicine—# MeToo," *New England Journal of Medicine*, (2018) 378, pp. 209-211.
25. L. Alcoff, 1991, "The problem of speaking for others." *Cultural Critique* 20 (1991), pp. 5-32.





# Ethical Challenges in Medical Community Internships: Perspectives from Medical Interns in the Philippines

AIMEE LORRAINE C. CAPINPUYAN AND RED THADDEUS D. MIGUEL

## Abstract

The Philippine community internship program, originally created to supplement the country's thinning health workforce while providing training to student doctors, poses a legal and ethical challenge for medical interns. Inherent characteristics of the program—such as financial disparities and burdens, the lack of supervision by senior doctors, the competence of student doctors, and short rotation times—can predispose interns to cause harm to the patients and communities they serve. As currently designed, the internship program has the capacity to leave interns unsupervised, at risk of legal ramifications, constantly questioning the correctness of their interventions, and perpetually straddling conflicting role virtues. By failing to ensure that the community internship program has appropriate safeguards in place, the government not only jeopardizes the welfare of interns but also threatens the quality and continuity of care that patients and communities receive, potentially violating their right to the highest attainable standard of health. One medical school recently started a novel internship program that could address the issues mentioned.

---

AIMEE LORRAINE C. CAPINPUYAN, BSc HSc, is a medical intern at the Ateneo School of Medicine and Public Health, Pasig, Philippines, where she is undertaking the Community Enhanced Internship Program.

RED THADDEUS D. MIGUEL, BSc HSc, MD, MBA, is an independent health policy researcher with focus in health financing.

Please address correspondence to Red Thaddeus D. Miguel. Email: red.upmanila@gmail.com.

Competing interests: Aimee Capinpuyan is currently enrolled as a medical intern at the Ateneo School of Medicine and Public Health. Red Miguel received his doctor of medicine from the same school.

Copyright © 2019 Capinpuyan and Miguel. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0>), which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

## Introduction

Through the Philippine community internship program, medical interns are posted at small-town health centers in select—typically poor—communities, where they act as junior physicians. The program's intentions are noble, tackling the lack of physicians in underserved communities while providing training to medical interns. However, inherent characteristics of the program pose ethical and legal challenges for medical interns. During the program, distraught interns find themselves in a position that could threaten the rights of the patients they encounter. We examine such situations using examples gathered from our own community internship experiences and those of our peers. We conclude by offering our insights on a potentially improved system recently implemented by the Ateneo School of Medicine and Public Health.

## The Philippine community internship

In the 1970s, the community internship was established as a component of the Comprehensive Community Health Program in the Philippines.<sup>1</sup> Interns were required to rotate in accredited community sites under the direct supervision of faculty members. While the original program was eventually phased out in the 1980s, the inclusion of community-based medical training became a formal requirement for medical colleges nationwide in 1994. During this time, the Association of Philippine Medical Colleges, the national organization that supervises and monitors internship programs, created guidelines for implementing the community internship. According to the guidelines, the internship program may take on the following forms: “a formal community health program of the hospital, a program of the local health department or health center, a school health program, a health program of NGOs, civic, and religious groups, and other creative community health programs.”<sup>2</sup> While there is flexibility in implementation, the most common format is a two-month rotation for interns.

## The ethical complexities of medical internships in communities

“Internship year,” which is a medical student's final year of formal training, has been found by several studies to be fraught with ethical and legal challenges. One study found five specific challenges: telling the truth, respecting patients' wishes, preventing harm, managing the limits of one's competence, and addressing the performance of others that is perceived to be inappropriate.<sup>3</sup> Another study found that the most common issues experienced by students were professionalism, confidentiality, the doctor-patient relationship, informed consent, and the doctor-peer relationship.<sup>4</sup> Further, the mistreatment and abuse of medical students by more senior staff can also add to these ethical challenges.<sup>5</sup> In the Philippines, these challenges seem to be magnified in light of several inherent limitations of the community internship program.

### *Inequalities and financial burdens*

Medical interns experience pressures from an entirely new work environment as they transition to their new community internship in conditions where systemic inequalities subject their poor patients to dire health outcomes. This makes the community internship program a difficult situation for both interns and the communities they serve.

According to a 2015 World Bank study, more than one-fifth of the Philippine population, or 22 million people, lives below the national poverty line.<sup>6</sup> Roughly 8.2 million people cannot afford basic food requirements. Economic inequities make poor Filipino households susceptible to employment shocks (such as job losses and lower wages) and health-related shocks (such as illness, death, and unplanned pregnancies).<sup>7</sup> Moreover, poor households often have limited access to basic services, such as sanitation, clean water, electricity, and household assets, including communication and mobility tools.<sup>6</sup> As a result, poor communities have weak bargaining power when it comes to accessing quality health care. For lack of better options, communities are eager to accept any additional health

resource that comes their way, including medical interns still in training.

The interns, on the other hand, usually work without pay at their assigned community health centers. In many cases, students pay out of pocket for daily transportation costs, medical equipment and medications for their health centers, and programs they wish to implement. Consequently, the quality of care interns bring to their communities could depend on their personal financial capacity.

### *Lack of supervision and role models*

In many iterations of the community program in the Philippines, interns are assigned to a local government-sponsored health center. Although health centers do have regular doctors in their employ, the thinning workforce in local health networks forces senior physicians to divide their time among several neighboring health centers. Consequently, it is not uncommon to have days where community interns are left to their own devices in the health centers. Even on days when physicians are present, the amount of support that interns receive from them is contingent on the individual physician's willingness to teach, as well as his or her workload. When interns are fortunate enough to be assigned to a health center with an accommodating consultant, cases are reviewed and lessons are shared regarding cases seen. Unfortunately, it is more often the case that overworked senior physicians are unable to be the role models that community interns need them to be.

In instances where there is a lack of supervision from a senior physician, the intern may be forced to take on the role of primary health care provider despite lacking a license to practice. This poses a legal quandary, as only those who have passed the Physician Licensure Exam are legally allowed to practice medicine, according to the Philippine Medical Act of 1959.<sup>8</sup> Interns—medical students who have completed the first four years of medical studies—are legally allowed to practice medicine only during epidemics or national emergencies, and even then only with special authorization by the Secretary of Health.<sup>8</sup> Furthermore, the lack of supervision has been found to potentially introduce unnecessary

harm to patients brought about by systematic errors, an inability to demonstrate compassion, and the provision of futile treatment.<sup>9</sup> Hence, the lack of supervision in the scenario of the Philippine community internship may compromise the safety of patients, as well as that of the larger community.

### *Competence of student physicians*

Interns' lack of experience and knowledge further enhances the risk of the internship program introducing harm to the communities being served. One example is the rotation system that is in place in most internship programs throughout the Philippines. Under this system, groups of interns rotate through different fields of medicine, including community medicine, over the course of the program. For example, a group may be in internal medicine one week, surgery the next month, radiology after that, and so on, until all rotations are completed. By the end of the year, every group would have experienced and learned from each rotation. If an intern is assigned a rotation schedule in which community medicine is last, then the intern brings many of the new skills, experiences, referral networks, and knowledge from past rotations. However, if the intern draws a rotation in which the community program is first, and he or she is not supervised, then the intern is left to rely on knowledge and skills from medical school, which may be insufficient for the cases encountered in the community.

To address knowledge gaps throughout the year, interns often develop referral systems among internship groups. These networks also arise from interns' fear of being ridiculed by senior consultants and their lack of access to supervising physicians. Interns consult with fellow interns instead of senior doctors, potentially leading to the propagation of false information or inappropriate management. Worse yet, erroneous practices that are not caught early on may even propagate through the next set of interns, given that it has become a custom for fourth-year medical students, before commencing their internship year, to turn to outgoing interns for notes and tips.

Lastly, community interns often prescribe

medications despite lacking a medical license. In such cases, interns write the health center doctor's name and license number on the prescription beside the intern's name. Some doctors entrust their name stamps to the health center interns for the express purpose of prescribing drugs in their absence. While formal studies have not been conducted on the safety of this practice, it is ethically and legally questionable to allow a medical student to prescribe medications.

### *Gaps in continuity of care*

Continuity of care can be defined as a seamless transition among health services and providers over time.<sup>10</sup> Ensuring continuity of care is essential for quality care, but its importance is largely unrecognized in the Filipino medical internship program. The current setup wherein interns rotate across fields, spending only two months at a time at community health centers, could lead to complications and adverse reactions caused by the prescribed treatment going unnoticed.<sup>11</sup> Similar to the case of short-term volunteerism, this set-up fails to achieve an optimal continuity of care, characterized by regular contact between providers and the communities they serve.

An example of this can be seen in our own experience. We once had an elderly patient who would routinely visit the health center for a refill of his hypertensive medications. He had an extremely hoarse voice that made him difficult to understand, but when probed for details about it, he would repeatedly insist, "I'm fine, I'm fine. Nothing is wrong with me." It was apparent that he simply wanted to receive his medications and leave. We later learned from the health center's regular doctor that this man was an old patient of hers who had been diagnosed with suspected laryngeal cancer. He needed urgent hospital attention but had always refused to seek such care out of fear of being intubated. This information was crucial in guiding our plans when he followed up a month later—we were able to counsel him regarding his condition, focusing on his hospital-related fears, with the goal of allowing him to make a more informed decision regarding his management. It was fortunate for us that the health center's doctor had

been around at the time; other interns, especially those who work as health centers' only doctors, know the struggle of managing chronic patients with an unclear clinical history.

One way to alleviate the effects of the rotation system is to have the outgoing community interns properly endorse their patients to the incoming group. Endorsements (also known as "handovers" or "handoffs") are when the outgoing team of caregivers relates crucial patient-specific information to the incoming team. Caregiver-to-caregiver endorsements are crucial in patient care, and ineffective handoff communication has been found to be the most common cause of adverse hospital events.<sup>12</sup> Accordingly, in rural settings, effective handover practices have been found to significantly improve perceptions of patient safety.<sup>13</sup> However, the reality is that patient endorsements rarely happen as interns rotate through their assigned fields. The high volume of patients seen at community centers makes endorsing each patient who needs long-term care a tedious and time-consuming task. Instead, interns tend to rely on patient records, which can vary in quality and often lack important data.

### Discussion

Coming from clerkship year, in which students are focused on fulfilling academic requirements and handling ward work, interns confront a complicated situation. All at once, the intern experiences overlapping roles: a health professional and a learner, a student and a member of the workforce. These coexisting expectations create tensions and can lay the ground for moral distress.

This phenomenon can be explained in the light of conflicting role virtues.<sup>14</sup> As student doctors, interns are expected to be benevolent, compassionate, truthful, just, humble, and self-sacrificing.<sup>15</sup> As medical learners, they are expected to prioritize cooperativeness, curiosity, commitment to one's education and development, responsibility, and motivation.<sup>16</sup> As employees (of the hospital or health center), they are expected to emphasize efficiency, flexibility, competence, and dedication to the job.<sup>17</sup> Interns want to do "good," but the



definition of “good” varies depending on the role. Often, characteristics inherent to the community internship program make it difficult for interns to simultaneously and equally uphold these many virtues, creating an internal conflict that precludes them from accomplishing the objective of the community internship program. Taking these roles together, the community intern is expected to be efficient, competent, and benevolent. However, practicing in extremely resource-deficient settings with high numbers of patients and little to no physician support can prevent interns from fulfilling this vision. Even in the presence of regular doctors, interns can still lack role models who exemplify the kind of humility, compassion, and courage needed to effectively practice in resource-limited settings. Thus, the entire experience causes unnecessary stress that could negatively affect interns’ mental health, their perception of what it means to be a physician, and the quality of care they provide to the community. As interns complete their studies, they are left to wonder whether they were indeed able to uphold any of their roles during the community internship program.

In the grand scheme of national health delivery, the Philippines, as a party to the International Covenant on Economic, Social and Cultural Rights, is obligated to uphold the rights of its constituents to attain “the highest standard of physical and mental health.”<sup>8</sup> Furthermore, the country’s Republic Act No. 11223 (more commonly known as the Universal Health Care Act) states that it is the “policy of the State to protect and promote the right to health of all Filipinos and instill health consciousness among them.”<sup>9</sup> For policy makers unaware of the aforementioned shortcomings of the community internship program, these internships appear to offer a magic bullet for strengthening the country’s weak medical workforce and producing excellent future physicians. In addition, the program seems to be aligned with the government’s mandate to improve health outcomes for communities. However, as described earlier, in its current iteration, the community internship program poses the risk of harm to patients and interns alike. By maintaining the flawed design of the program, the government

is failing to uphold its legal obligation to provide health for all.

The Philippines’ community internship program has the potential to provide much-needed care where health inequities thrive, as well as to hone the abilities of the nation’s future physicians. However, as currently designed, it also has the capacity to leave interns unsupervised, at risk of legal ramifications, constantly questioning the correctness of their interventions, and perpetually straddling conflicting role virtues. When the government fails to ensure that the community internship program has appropriate safeguards in place (for example, an adequate number of senior physicians, compensation for interns, and proper referral systems), it jeopardizes not only the welfare of interns but also the rights of communities. For patients and their communities, the design of the internship program threatens the quality and continuity of care that they receive, potentially violating their right to the highest attainable standard of health.

### Redefining the community internship program

As discussed, medical students’ community internship experiences can be laden with ethical and legal challenges stemming from the government’s failure to ensure adequate support for interns. In turn, the situation of the interns and the conditions in which they work have the potential to harm patients in the communities being served. As we wait for the government to take measures to improve the national curriculum, one medical school is currently testing a restructured community internship program that, if successful, could provide a desirable alternative for other medical schools.

The Ateneo School of Medicine and Public Health, established in 2012, recently created a program to address these challenges. Recognizing the immense potential of health centers to serve as effective instructional settings for medical education, the school partnered with the Quezon City local government to create a novel community track for fifth-year medical students called the Community-Enhanced Internship Program (CEIP).

Under the CEIP, fifth-year medical students rotate between a partner health center and the school's partner hospitals for 12 months. At the health center, their main task is to run a community clinic where specialty consultations are made available through the presence of consulting faculty from various fields of medicine.

The program innovates on the usual community internship format in three ways. First, interns are provided constant supervision through the regular presence of consulting faculty in the health center. Unlike in most community internships, in which interns are left to their own devices at community health centers, this method ensures that interns carry out safe and appropriate patient management. Second, CEIP interns spend a total of six months in their community instead of the usual two. The longer duration of the program allows for closer follow-up of patients and minimizes the need for patient handoffs. Third, CEIP interns' hospital rotations alternate with their community rotations on a monthly basis, unlike the usual program in which interns spend two consecutive months in a community and ten consecutive months in a hospital. The alternating community and hospital months in the CEIP allow interns to supplement the knowledge and skills learned from hospitals with that learned from their communities, and vice versa. In this way, the CEIP may offer an answer to the ethical challenges described earlier, for its constant supervision of interns, longer program duration, and alternating hospital-community rotations aim to promote quality and safe patient care, with the possible long-term effect of upholding communities' rights to quality health care. However, as of writing, the new program is only on its tenth month of operations, with a pioneer cohort consisting of just 12 interns rotating at one health center. The school administration plans to continue the program for two more cohorts before conducting an evaluation.

In conclusion, medical students' completion of their community internship can be fraught with ethical and legal issues. Interns—with their multiple and sometimes conflicting roles as clinicians, learners, and employees—are placed in a complex

ethical position when they practice medicine in poor and vulnerable communities. The lack of support for interns perpetuates these problems, consequently threatening the rights of the patients they serve. The Ateneo School of Medicine and Public Health's CEIP may provide a desirable alternative to the existing format of community internships given its longer program duration and more extensive supervision scheme, but in light of the novelty of the program, no solid recommendations can yet be made. If successful in alleviating the limitations of the current community program, the government may consider implementing the CEIP design, or a version of it, in all medical schools with the hopes of upholding its constituents' right to the highest attainable standard of health.

## References

1. C. Dimacali, "The University of the Philippines College of Medicine: Pioneer in medical education innovations in the Philippines," *Acta Medica Philippina* 51/4 (2017), pp. 360–362.
2. R. L. Arcadio, "R. L. Arcadio to all hospital directors of APMC accredited internship programs and all deans of medical schools," (July 31, 2018).
3. R. McDougall and D. K. Sokol, "The ethical junior: A typology of ethical problems faced by house officers," *Journal of Royal Society of Medicine* 101/2 (2008), pp. 67–70.
4. N. N. Fard, F. Asghari, and A. Mirzazadeh, "Ethical issues confronted by medical students during clinical rotations," *Medical Education* 44/7 (2010), pp. 723–730.
5. F. Cook, V. M. Arora, K. A. Rasinski, et al., "The prevalence of medical student mistreatment and its association with burnout," *Academic Medicine* 89/5 (2014), pp. 749–754.
6. World Bank, *Making growth work for the poor: A poverty assessment for the Philippines* (Washington, DC: World Bank, 2018).
7. J. R. Albert, J. C. Dumagan, and A. Martinez, Jr., "Inequalities in income, labor, and education: The challenge of inclusive growth," Philippine Institute for Development Studies Discussion Paper Series (2015). Available at <https://dirp4.pids.gov.ph/webportal/CDN/PUBLICATIONS/pids-dps1501.pdf>.
8. Republic of the Philippines, *Republic Act No. 2382 (as Amended by Republic Act No. 4224): The Medical Act of 1959 (1959)*. Available at [https://www.lawphil.net/statutes/repacts/ra1959/ra\\_2382\\_1959.html](https://www.lawphil.net/statutes/repacts/ra1959/ra_2382_1959.html).
9. P. A. Clark, "What residents are not learning: Observations in an NICU," *Academic Medicine* 76/5 (2001), pp. 419–424.

10. H. J. Biem, H. Hadjistavropoulos, D. Morgan, et al., "Breaks in continuity of care and the rural senior transferred for medical care under regionalization," *International Journal of Integrated Care* 3 (2003), p. e03.
11. I. Bauer, "More harm than good? The questionable ethics of medical volunteering and international student placements," *Tropical Diseases, Travel Medicine and Vaccines* 3/5 (2017).
12. E. Manias, F. Geddes, B. Watson, et al., "Perspectives of clinical handover processes: A multi-site survey across different health professionals," *Journal of Clinical Nursing* 25/1 (2015), pp. 1-2.
13. D. Piper, J. Lea, C. Woods, and V. Parker, "The impact of patient safety culture on handover in rural health facilities," *BMC Health Services Research* 18/1 (2018), p. 889.
14. R. McDougall, "Understanding doctors' ethical challenges as role virtue conflicts," *Bioethics* 27/1 (2013), pp. 20-27.
15. J. F. Drane, *Becoming a good doctor: The place of virtue and character in medical ethics* (Kansas City: Sheed and Ward, 1988), p. 32.
16. M. Parker, "Autonomy, problem-based learning and the teaching of medical ethics," *Journal of Medical Ethics* 21 (1995), p. 307.
17. L. Ryan, "The ten qualities of outstanding employees," *Forbes* (August 20, 2018). Available at <https://www.forbes.com/sites/lizryan/2017/08/20/the-ten-qualities-of-outstanding-employees/#2afaoa59738f>.
18. Committee on Economic, Social and Cultural Rights, General Comment No. 14, The Right to the Highest Attainable Standard of Health, UN Doc. E/C.12/2000/4 (2000).
19. Republic of the Philippines, *RA no. 11223: An Act Instituting Universal Health Care for All Filipinos, Prescribing Reforms in the Health Care System, and Appropriating Funds Therefor* (2019). Available at <https://www.officialgazette.gov.ph/downloads/2019/02feb/20190220-RA-11223-RRD.pdf>.



# Addressing Ethical Quandaries in Undergraduate Student-Led Global Health Trips: Design, Implementation, and Challenges of Guidelines by Students for Students

JACOB ROBLE, LAURA BLOCK, MASON FLANNAGAN, ERIC OBSCHERNING, AND  
LORI DIPRETE BROWN

## Introduction

Interest in global health at American universities has increased dramatically over the past 15 years.<sup>1</sup> International fieldwork is an integral component of global health programming, with students traveling for humanitarian reasons, learning opportunities, and a need to meet graduate program admissions requirements.<sup>2</sup> For example, 73% of American medical schools require or encourage clinical experience by applicants despite committee members' "significant concern" about the potential for unlicensed students providing care, such as surgical procedures, to patients in other countries during international health trips.<sup>3</sup> The academic community has critiqued the ethical challenges of these short-term trips, but to date undergraduate students are absent from these discussions.<sup>4</sup>

Mirroring national trends, the University of Wisconsin-Madison (UW-Madison) has experienced growth in global health programming, including an undergraduate- and graduate-level global health minor with faculty-mentored fieldwork. These programs involve rigorous screening, training, reflection, and discussion of cross-cultural issues and ethics. During travel, faculty emphasize learning as the primary goal. Outside of global health programming, students engage in extracurricular global health work through registered student organizations (RSOs). No well-recognized mechanisms exist for preparing students traveling with RSOs, which, by design, operate with autonomy and self-governance.<sup>5</sup> The university's role and responsibility in providing guidance for these trips is ambiguous.

UW-Madison has more than 1,000 RSOs.<sup>6</sup> Of these, 30% have a health focus and 10% a specific interest in global health.<sup>7</sup> The number and nature of short-term trips outside of university programming are not tracked,

---

JACOB ROBLE, BS, is a recent graduate of the University of Wisconsin-Madison College of Letters and Sciences, Madison, USA.

LAURA BLOCK, BS, is a current student at the University of Wisconsin-Madison School of Nursing, Madison, USA.

MASON FLANNAGAN is an undergraduate student at the University of Wisconsin-Madison College of Letters and Sciences, Madison, USA.

ERIC OBSCHERNING, BS, is a graduate of the University of Wisconsin-Madison College of Letters and Sciences, Madison, USA.

LORI DIPRETE BROWN, MSPH, MTS, is associate director of the Global Health Institute and a distinguished faculty associate in civil society and community studies in the School of Human Ecology at the University of Wisconsin-Madison, USA.

Please address correspondence to Jake Roble. Email: [roblejake@gmail.com](mailto:roblejake@gmail.com).

Competing interests: None declared.

Copyright © 2019 Roble, Block, Flanagan, Obscherning, and DiPrete Brown. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted noncommercial use, distribution, and reproduction in any medium, provided the original author and source are credited.



but their existence is known among students and faculty. RSO members share stories of providing unqualified care when recruiting, reflecting in class, or crafting post-baccalaureate applications. Details have not been disclosed to protect patient and student confidentiality, but comparable stories of students delivering babies, providing medications requiring long-term monitoring, and assisting in surgical procedures have been reported nationally.<sup>8</sup> Additionally, 85% of pre-health advisors nationally report knowledge of these undergraduate trips, and 89% acknowledge concern about students providing unqualified care.<sup>9</sup>

Though guidelines for global health trips exist, the majority are directed toward graduate and medical students.<sup>10</sup> Some organizations, such as the Association of American Medical Colleges, have responded by tailoring guidelines to undergraduate students but do not present mechanisms for translating such guidelines to the extracurricular context.<sup>11</sup> The Forum on Education Abroad has also developed guidelines for undergraduate global health trips, but these guidelines target institutions, not students.<sup>12</sup> None of the guidelines are tailored to independent bodies such as RSOs, even though extracurricular global health trips take place at universities across the country. Universities may be constrained in addressing RSO trips due to the legal void within which RSO-led trips take place.

Recognizing this void, we developed guidelines for undergraduate RSOs and methods for their distribution. Our work was inspired and informed by a variety of exemplars, traditional medical ethics, and human rights principles. While not a systematic rights-based program, our effort is compatible with further development in this direction over time. We paid particular attention to Thomas Pogge's ethical framework—a global expansion of Rawlsian philosophy—which recognizes how interconnected global systems and institutions create inequitable distributions of power, resources, and suffering.<sup>23</sup> Additionally, we relied heavily on traditional medical ethics, which are guided by the Hippocratic Oath and grounded in absolute virtues such as empathy and beneficence.<sup>14</sup> However, medical ethics are largely

unidirectional in nature, centering on patients and certain aspects of their health while often missing broader social determinants of health.<sup>15</sup> A human rights framework bridges this gap, locating health within a broader context of interdependent and indivisible rights and recognizing a larger number of players in the global arena: providers, students, and patients alike.<sup>16</sup> Further, the Universal Declaration of Human Rights makes clear that all humans have a right to basic entitlements, including health.<sup>17</sup> The delivery of unqualified care challenges the human right to accessible, affordable, appropriate, and quality health care as stipulated in General Comment 14 of the United Nations Committee on Economic, Social and Cultural Rights.<sup>18</sup> Ethical lapses challenge patients' rights and dignity. This resonated with our personal convictions regarding social justice, which are informed largely by the Alma-Ata Declaration and the Universal Declaration of Human Rights.<sup>19</sup>

This paper describes our (1) design of guidelines for undergraduate students traveling on short-term global health trips outside of academic programming, and (2) implementation of a novel, sustainable, student-led program to engage with and discuss these guidelines.

## Methods

In 2014, we discussed the need for ethical guidelines and avenues for their distribution. We reviewed existing guidelines, theoretical underpinnings, and models of distribution; conducted an internal analysis to identify stakeholders; and reviewed policies regarding RSO oversight, travel, and funding. Finally, we tailored these guidelines to undergraduate RSOs and constructed a program for the guidelines' distribution. Evaluation was performed via surveys and informed program improvements.

The design process focused on fostering undergraduate students' awareness of ethical challenges and the need to prevent harm during travel. Given the self-governing and autonomous nature of RSOs, we chose a reflective process of learning and discernment rather than a regulatory approach. The voluntary, extracurricular nature of RSO ac-

tivities also influenced the design, triggering the development of a brief educational program to raise awareness and foster positive decision-making. The aim was to create pragmatic and accessible guidelines and accompanying educational program based on a set of central driving principles.

## Results

### *Literature review findings*

Our literature review revealed a number of guidelines, perspective pieces, and case studies, which we analyzed for key components and principles. Of note was John Crump and Jeremy Sugarman’s guidelines for global health training.<sup>20</sup> Since performing our original literature review in 2014, there has been growth in the global health ethics field, illustrated by a recent scoping review of guidelines for global health trips.<sup>21</sup>

### *Internal analysis findings*

At UW-Madison, we identified 172 RSOs with “global health” in their name or description, 348 with “pre-health” in their name, and 156 with a self-described “medical” interest. Most of these

RSOs function as independent entities. Others function as chapters of national volunteer organizations; however, student members of these RSOs often described a paucity of guidance from the parent organizations. The UW-Madison student government allocates funding to RSOs for travel but does not have additional screening for health-related trips.

### *Alignment with ethical and human rights frameworks*

By going beyond traditional medical ethics, we engaged with a broad body of literature and subsequently reflected on a wide set of concepts and values (Table 1) throughout the ethical guidelines and accompanying educational program, both implicitly and explicitly.<sup>22</sup>

### *Guideline development*

Eighteen student organizations and several mentors from the UW-Madison Global Health Institute, Center for Pre-Health Advising, and School of Medicine and Public Health met to develop the ethical guidelines, which were framed by a preamble inspired by a review of key ethical and human

TABLE 1. Ethical and human rights frameworks used in the guidelines and accompanying educational program

Component	Ethical and human rights concepts and values
Preamble to the guidelines and educational program	<ul style="list-style-type: none"> <li>• Ideas related to the interconnected global systems that shape the distribution of resources and outcomes</li> <li>• Human rights concepts relating to the notions of universality, equity, justice, and systems thinking, with an emphasis on marginalized populations</li> <li>• Human rights emphasis on the meaningful participation of all stakeholders</li> <li>• Right to health</li> </ul>
Educational program for distribution of guidelines	<ul style="list-style-type: none"> <li>• Ideas related to the interconnected global systems that shape distribution of resources and outcomes</li> <li>• Human rights concepts relating to the inviolable nature of human dignity, and notions of universality, equity, justice, and systems thinking.</li> <li>• Human rights concepts recognizing health as interdependent, indivisible, and inalienable to other rights (aligns with understandings of social determinants of health)</li> <li>• Right to health</li> <li>• Right to highest standard of care</li> <li>• Right to privacy and confidentiality</li> <li>• Right to non-discrimination and equality</li> <li>• Right to information</li> </ul>
Guidelines	<ul style="list-style-type: none"> <li>• Right to health</li> <li>• Right to highest standard of care</li> <li>• Right to privacy and confidentiality</li> <li>• Right to non-discrimination and equality</li> <li>• Right to information</li> </ul>
Document for planning partnerships	<ul style="list-style-type: none"> <li>• Human rights concepts relating to meaningful participation and inclusion, universality, and equity</li> </ul>

rights frameworks (Table 2). Our strategies for designing the preamble and incorporating it into the guidelines and programming are highlighted.

As a result of several meetings, we drafted 26 ethical considerations pertaining to five stages of travel (Table 3). These considerations largely represent normative principles and practical steps. The Office of Legal Affairs reviewed the final draft, adding a statement disclaiming any responsibility or liability and advising a change in the title from “Ethical Guidelines” to “Ethical Considerations.”

### *Educational program development and implementation*

The guidelines were delivered through a one-hour educational program conducted via a self-directed, lateral approach, as informed by andragogical learning theory.<sup>23</sup> The educational program aimed to begin a conversation that would continue throughout the planning and implementation of any subsequent RSO travel. The approach incorporated teaching principles specific to service-learning trips, focusing on (1) mitigating power dynamics via a peer-to-peer approach, (2) reframing ethics as a learning process on the individual and collective level, (3) approaching conflict as an “opportunity,” not a “problem,” and (4) communicating strategically in a supportive, non-punitive manner.<sup>24</sup> Attendance was incentivized by providing food,

opportunities to engage with faculty, and a certificate of program completion. Student leaders also worked with the UW-Madison student government to draft a bylaw amendment that would require student groups to complete the educational program before receiving travel grants for global health trips. The bylaw amendment passed with unanimous support.

We reached out to all global health RSOs at the start of each year to offer the program, and between fall 2016 and spring 2017 offered the program three times and provided additional individual meetings. In total, 23 student organization leaders completed the program. Each leader made a verbal commitment to review the ethical considerations, articles, and case studies with their larger groups. Altogether, these leaders represented upwards of 1,500 undergraduate students.

During the program, authors and RSO student leaders engaged in conversation on the principles underlying the preamble and guidelines. Seven distinct principles and values were identified (Table 4).

The effect of requiring RSOs to complete the educational program to receive travel grants was assessed through a review of student government records. Of the 23 student organizations completing the program during the 2016–2017 pilot year, four had applied for travel grants through the student government. Upon review, these were the same

TABLE 2. Preamble to the ethical guidelines and accompanying educational program

Preamble text	Strategies for bringing the preamble to life
<p><i>The students of the University of Wisconsin-Madison are committed to the ethical and intellectual exercise of the Wisconsin Idea—the project of making the benefits of the university available to all members of the state of Wisconsin.</i></p> <p><i>The Wisconsin Idea shapes how we as students engage in global health activities. Global Health is the realization that all humans have a fundamental right to health and that global forces affect individual and community health. Striving toward global health equity requires us to understand that the causes and consequences of poor health in individuals and communities transcend national, socioeconomic, and political boundaries.</i></p> <p><i>When we work with organizations that provide healthcare to communities in the United States or abroad, the primary role of students is to observe, listen, and learn so that they may better understand the nature of global health inequalities, the barriers to access that marginalized communities face, and the systemic problems that perpetuate these disparities.</i></p> <p><i>The creation of these ethical considerations can help students to plan and participate ethically in service trips abroad while building relationships to strengthen local capacity, minimize risk, and maximize short- and long-term benefits to the local and global communities whom they serve.</i></p>	<p><b>Strategies for preamble design</b></p> <ul style="list-style-type: none"> <li>• Drafted by 18 student organization leaders involved in global health</li> <li>• Approved by all stakeholders involved in the program</li> </ul> <p><b>Strategies for preamble implementation</b></p> <ul style="list-style-type: none"> <li>• Preamble appears at the beginning of the guidelines in both print and online versions</li> <li>• Preamble incorporated into all educational materials</li> <li>• Preamble read aloud during educational program, with critical discussion of its content afterward</li> </ul>

four organizations flagged in student government records as seeking finance for global health trips. The remaining 19 RSOs indicated the following reasons for attendance: plans to travel with personal funding, plans for future travel grant applications, and interest in the topic.

### *Challenges to design and implementation*

Challenges to design were many and included the following: understanding legal ramifications related to the autonomy of RSOs, locating RSO numbers and data, and securing institutional support. In response to student leader turnover, we requested and

TABLE 3. Ethical considerations across stages of travel

Stage of travel	Key considerations	Associated task
Stage 1: Key guidelines to follow when considering a volunteer trip	<ol style="list-style-type: none"> <li>1. Effectively screen and recruit students</li> <li>2. Identify stakeholders</li> <li>3. Vet local partner organization</li> <li>4. Create a planning document with partner organization</li> <li>5. Budget realistically</li> </ol>	<ul style="list-style-type: none"> <li>• Complete document for planning partnerships</li> </ul>
Stage 2: Strategies for developing cultural knowledge about partner community and organization	<ol style="list-style-type: none"> <li>6. Mitigate language barriers and learn key phrases in local language(s)</li> <li>7. Review local cultural and social norms on health care</li> <li>8. Consult with experts about local culture</li> <li>9. Develop training materials for students</li> <li>10. Reinforce purpose during training: to learn and observe</li> </ol>	<ul style="list-style-type: none"> <li>• Conduct community-specific background research</li> </ul>
Stage 3: Guidelines to consider when planning the trip's logistics	<ol style="list-style-type: none"> <li>11. Understand every team member's responsibilities and roles</li> <li>12. Understand the health risks and resources</li> <li>13. Pack properly</li> <li>14. Consider the ethics and unintended consequences of donations in local community</li> <li>15. Secure a translator</li> </ol>	<ul style="list-style-type: none"> <li>• Review health and safety resources</li> <li>• Determine proper clothing and gear</li> <li>• Review donation guidelines</li> </ul>
Stage 4: Guidance on decision-making and conflict resolution during the trip	<ol style="list-style-type: none"> <li>16. Schedule daily planning and debriefing sessions</li> <li>17. Utilize a translator</li> <li>18. Forbid patient care and treatment by students</li> <li>19. Clarify to community partners and local community members that students are not clinicians</li> <li>20. Remind students to say "no" to inappropriate requests</li> <li>21. Be sensitive to local norms around gender and sexuality</li> <li>22. Prepare for and mitigate cultural misunderstandings</li> <li>23. Maintain patient privacy and obtain consent</li> </ol>	<ul style="list-style-type: none"> <li>• Compile a trip-specific plan</li> <li>• Prepare debrief documents and activities</li> </ul>
Stage 5: Guidelines to follow when returning home from the trip	<ol style="list-style-type: none"> <li>24. Debrief and evaluate the experience</li> <li>25. Follow up with the partner organization and community</li> <li>26. Check in regularly and maintain partnership obligations</li> </ol>	<ul style="list-style-type: none"> <li>• Review the ethics of photography</li> </ul>

(<https://prehealth.wisc.edu/service-trips-abroad/>)

TABLE 4. Underlying principles and values of the guidelines and educational program

Principle or value	Connection to ethical and human rights frameworks
Consider role in harm prevention and reduction	<ul style="list-style-type: none"> <li>• Right to health</li> <li>• Non-maleficence, beneficence</li> </ul>
Define and follow scope of practice	<ul style="list-style-type: none"> <li>• Right to highest standard of care (acceptability and quality)</li> <li>• Non-maleficence, beneficence</li> </ul>
Apply the same skills and training criteria overseas as in home country	<ul style="list-style-type: none"> <li>• Right to highest standard of care (quality)</li> </ul>
Respect individual privacy and confidentiality	<ul style="list-style-type: none"> <li>• Right to privacy and confidentiality</li> </ul>
Be conscious of differing cultures, power dynamics, and social hierarchies	<ul style="list-style-type: none"> <li>• Right to highest standard of care (acceptability)</li> </ul>
Identify and apply a higher level of protections to vulnerable populations, such as children, women, minorities, and the poor	<ul style="list-style-type: none"> <li>• Right to non-discrimination and equality</li> <li>• Right to highest standard of care (accessibility)</li> <li>• Non-maleficence, beneficence</li> </ul>
Consider equity and sustainability of programs	<ul style="list-style-type: none"> <li>• Right to highest standard of care (availability and accessibility)</li> </ul>

were granted support for a long-term internship within the Center for Pre-Health Advising.

Challenges to implementation included busy student schedules, difficulty reaching the targeted student audience, navigating the disclosure of unethical practices, and barriers to comprehension for attendees. Comprehension was hindered by the difficulty of the content, cognitive dissonance, and the belief that “some help is better than none.” Despite this, students demonstrated interest and willingness to monitor and enforce their own ethical practice.

## Discussion

The success to date and future potential of the educational program are likely due to unique features of its design that draw on adult learning principles and participatory frameworks.<sup>25</sup> Rather than employing regulatory language and a punitive framework, the program frames the student journey as a “coming into awareness” and situates ethical quandaries as a part of global health work that all must navigate using self-regulation and discernment. Further, a student-led, peer-to-peer advising model with an emphasis on participatory learning and culture change mitigates hierarchal power dynamics that can undermine trust. Anecdotal evidence from RSO leaders on critical conversations among members and with parent volunteer organizations has suggested that this design may have the potential to change individual and group behavior. In future project phases, pre- and post- program evaluation will be necessary to accurately capture the impact of this model at scale and the effect on student organization culture.

Equally important is the pragmatic, procedural guidance that is complemented by discussions on ethics and human rights principles. During the educational program, the notion of justice—highlighted in human rights frameworks—resonated with student participants. Further, the application of a human rights framework, particularly the inviolate and inalienable dignity of people, and the AAAQ (Availability, Accessibility, Acceptability and Quality) standards helped students think

critically about their beliefs that “one’s poverty outweighs one’s dignity.” Future work will make these ideas explicit throughout the guidelines and educational program, having students engage directly with key human rights principles rather than confining the principles to the discernment exercises and implicit design.

Finally, to ensure coverage of RSOs at the university level, a better screening process is needed to identify all RSOs engaging in independent global health trips. Groups that do not brand their trips as “health trips” or that do not request funding from RSO resource pools may not be identified with current procedures.

## Conclusion

This paper describes the first student-led development and implementation of ethical guidelines for non-academic RSO global health trips and details the challenges to design and uptake for universities and students wishing to replicate the model.

The ability to partake in a global health trip is predicated on a host of material and cultural privileges, including disposable income to travel internationally while attaining a college degree. Beyond this is a broader privilege that gives one power in influencing another’s well-being. By engaging internationally with marginalized populations in health-related settings, students enter into spaces with the power to make decisions that will affect the health of individuals and communities. Presented with difficult choices, they need an ethical lens through which to evaluate the impact on the people they wish to serve. They need to consider whether those choices protect or challenge those individuals’ rights to health and quality care. Our program—by bringing to light the unintended consequences of unqualified care, disjointed interventions, and misbalanced partnerships in a non-punitive, peer-to-peer format—helps undergraduate students do just that. By collectively reviewing the preamble of the ethical considerations at the outset of the program, students begin their intellectual journey grounded in the understanding that health is a human right. This conviction is the *sine qua non* of



our program.

Our initiative addresses ethical breaches by RSOs at UW-Madison, yet this problem extends to other universities throughout the United States where similar legal voids exist. A program by students for students can enter critical spaces and discussions that institutions and staff, by nature, cannot traverse. This both increases the potential for impactful change and reduces the barrier for program replication. There is no shortage of passionate undergraduate students seeking an opportunity to make a difference locally and globally.

Replication at other universities would require adaptation of the guidelines and educational program and consideration of local policies and stakeholders. Additionally, a careful review of the challenges to design and implementation might improve future rollout. The proliferation of student-led systems such as this one would ensure that these commonplace trips continue to spur interest in global health and foster cross-cultural collaboration without compromising the ideals of justice and equity at the heart of global health and human rights.

## Acknowledgments

We would like to dedicate this work to the late Robin Mittenthal, mentor and advisor to countless global health students and champion of ethical and sustainable relationships between communities and universities. In addition, we would like to thank Emi Kihslinger, Daniel Simon, James Conway, Sweta Shrestha, Susan Nelson, Diya Selimi, Sarah Paige, Claire Wendland, and the student government of UW-Madison.

## References

1. J. A. Crump, J. Sugarman, and the Working Group on Ethics Guidelines for Global Health Training, "Ethics and best practice guidelines for training experiences in global health," *American Journal of Tropical Medicine and Hygiene* 83/6 (2010), pp. 1178-1182.
2. D. Holmes, L. E. Zayas, and A. Koyfman, "Student objectives and learning experiences in a global health elective," *Journal of Community Health* 37/5 (2012), pp. 927-934.
3. Group on Student Affairs, Committee on Admissions, *Clinical experiences survey summary* (Washington DC: As-

sociation of American Medical Colleges, 2016).

4. M. DeCamp, "Scrutinizing global short-term medical outreach," *Hastings Center Report* 37/6 (2007), pp. 21-23.
5. University of Wisconsin-Madison, *Student organization resource and policy guide - UW-Madison* (2018). Available at <https://guide.cfli.wisc.edu>.
6. University of Wisconsin-Madison, *Organization - Wisconsin Involvement Network (WIN)* (2018). Available at <https://win.wisc.edu/organizations>.
7. UW-Madison Wisconsin Involvement Network, *Search results* (2019). Available at <https://win.wisc.edu/organizations?categories=10873&query=global%20health>.
8. K. Fischer, "Some health programs overseas let students do too much, too soon," *Chronicle of Higher Education* (2013). Available at <https://www.chronicle.com/article/Overseas-Health-Programs-Let/142777>.
9. J. Evert, T. Todd, and P. Zitek, "Do you GASP? How pre-health students delivering babies in Africa is quickly becoming consequentially unacceptable," *Advisor* (2015).
10. J. N. Lasker, M. Aldrink, R. Balasubramaniam, et al., "Guidelines for responsible short-term global health activities: Developing common principles," *Globalization and Health* 14/18 (2018). Available at <https://doi.org/10.1186/s12992-018-0330-4>.
11. Association of American Medical Colleges, *Guidelines for premedical and medical students providing patient care during clinical experiences abroad* (Washington, DC: Association of American Medical Colleges, 2011).
12. Forum on Education Abroad, *Guidelines for undergraduate health-related experiences abroad* (Carlsisle: Forum on Education Abroad, 2018).
13. T. Pogge, *World poverty and human rights: Cosmopolitan responsibilities and reforms* (Cambridge: Polity Press, 2002), pp. 15-16.
14. R. Baker, "The history of medical ethics," in W. F. Bynum and R. Porter (eds), *Companion encyclopedia of the history of medicine* (London: Routledge, 1993), pp. 852-887.
15. T. Ezer and J. Cohen, "Human rights in patient care: A theoretical and practical framework," *Health and Human Rights* 15/2 (2013) pp. 7-19.
16. United Nations Children's Fund, *Human rights-based approach to programming* (New York: United Nations Children's Fund, 2003), pp. 1-3.
17. Universal Declaration of Human Rights, G.A. Res. 217A (III) (1948), art. 25.
18. Committee on Economic, Social and Cultural Rights, General Comment No. 14, The Right to the Highest Attainable Standard of Health, UN Doc. E/C.12/2000/4 (2000), art. 12.
19. Declaration of Alma-Ata, International Conference on Primary Health Care (1978); Universal Declaration of Human Rights, G.A. Res. 217A (III) (1948).
20. Crump et al. (see note 1).
21. Lasker et al. (see note 10).
22. FXB Center for Health and Human Rights, *Health and*

*human rights resource guide* (Cambridge, MA: FXB Center for Health and Human Rights, 2019). Available at <https://www.hhrguide.org/2014/02/27/table-a-and-b-patient-care>.

23. M. S. Knowles, *The modern practice of adult education: From pedagogy to andragogy* (Englewood Cliffs, NJ: Cambridge Adult Education, 1988).

24. W. B. Ventres and C. L. Wilson, "Beyond ethical and curricular guidelines in global health: Attitudinal development on international service-learning trips," *BMC Medical Education* 15/68 (2015).

25. Knowles (see note 23).

## INTRODUCTION

# Invoking Health and Human Rights in the United States: Museums, Classrooms, and Community-Based Participatory Research

SARAH S. WILLEN

The United States is rough terrain for those aiming to stake health-related human rights claims on domestic soil. Less than a decade ago, the passage of the 2010 Patient Protection and Affordable Care Act (ACA), which was designed as a massive expansion of insurance-based health coverage, led some health and human rights scholars to wax optimistic. The ACA—the Obama administration’s signature piece of legislation—passed by a razor-thin margin in US Congress. For human rights optimists, this legislation deserved praise for adopting “significant national reforms consistent with human rights norms” in a manner “Corresponding with international law, [and] following both the spirit and substance of the UDHR [Universal Declaration of Human Rights] and ICESCR [International Covenant on Economic, Social, and Cultural Rights].”<sup>1</sup> As pessimists were quick to point out, however, the ACA’s protections have always been “inherently unstable.”<sup>2</sup> First, this market-based arrangement grounds access to health care in a statutory right—in other words, a right that can be modified or revoked. In addition, it sidesteps international norms and commitments precisely “by avoiding the specific language of rights and obligations of international law.”<sup>3</sup>

Early predictions of the ACA’s promise from a human rights standpoint are thus difficult to reconcile with current realities. Some aspects of the law have gained wide popularity, especially its requirement to ensure health coverage for people with “pre-existing conditions.” During the first two years of the Trump administration, however, the Republican-led Congress sought repeatedly to undermine the ACA and erode its protections through court challenges, budgetary obstruction, and obfuscation about the nature and stipulations of the law itself. Numerous attempts to “repeal and replace” the ACA failed, and these efforts effectively stopped after the Democratic party took control of the US House of Representatives in the 2018 midterm elections. Meanwhile, arguments supporting a human right to health have gathered support from a small, politically liberal segment of the US electorate, especially since the presidential election of 2016.<sup>4</sup>

Although the country’s overall legal and policy climate is no more hospitable to health-related human rights claims now than before the passage of the ACA, this special section shares evidence that human rights can “travel” and transform even in settings where they lack legal traction, including the United States.<sup>5</sup> As these papers demonstrate, human rights can function beyond the spheres of law and policy as a power-

---

SARAH S. WILLEN, PhD, MPH, is an associate professor of anthropology and director of the Research Program on Global Health and Human Rights at the Human Rights Institute, University of Connecticut, Storrs, Connecticut, United States.

Please address correspondence to Sarah S. Willen. Email: sarah.willen@uconn.edu.

Competing interests: None declared.

Copyright © 2019 Willen. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted noncommercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

ful “idiom of social justice mobilization for health” by introducing new terms and concepts, deepening awareness of historical legacies, and proposing new narrative frames for interpreting current and past situations of disparity and injustice.<sup>6</sup>

This special section looks beyond the juridical domain to explore three cases in which unconventional encounters with human rights spurred non-specialists—that is, members of the American public—to contemplate the relationship between health and human rights. In the first case, I write about an exhibition with a provocative title at a federal museum: “Health Is a Human Right: Race and Place in America.” This exhibit was designed to commemorate the 25th anniversary of the Office of Minority Health and Health Equity at the US Centers for Disease Control and Prevention (CDC) in 2013. In the second paper, Bisan Salhi and Peter J. Brown analyze a pedagogical attempt to spark engagement with human rights concepts among US undergraduate students of global health. In the third paper, Nadia Gaber investigates two efforts to use community-based participatory research strategies to help protect and fulfill residents’ right to water in the American cities of Flint and Detroit, Michigan. Authors of all three papers are medical anthropologists with cross-training in public health or clinical medicine, and all employ qualitative research methods, including audio-recorded interviews, open-ended surveys, and participant observation.

By exploring how human rights principles and logics can reverberate in extra-juridical spaces, papers in this section draw on critical human rights scholarship to train their gaze on what anthropologist Richard Wilson calls the “social life of rights.” For Wilson, it is necessary to “look beyond the formal, legalistic, and normative dimensions of human rights, where they will always be a ‘good thing,’” and consider “how rights are transformed, deformed, appropriated, and resisted by state and societal actors when inserted into a particular historical and political context.”<sup>7</sup> In a similar vein, Peggy Levitt and Sally Engle Merry call attention to the “vernacularization” of human rights discourse by local actors, and Mark

Goodale advocates for a “skeptical distance from the exalted claims of human rights” while analyzing the “different registers through which the idea of human rights is conceived.”<sup>8</sup>

By exploring the social life of rights in museum, classroom, and citizen-science contexts, this special section sheds light on the potential as well as the limits of human rights frames in confronting health inequities and injustices in the United States. Through their analyses, the authors engage several important questions: What’s at stake in invoking the human right to health in conversations about health inequities in the United States? What obstacles do US researchers, public health professionals, and activists face in attempting to confront domestic health inequities and injustices using a human rights idiom? Finally, what new opportunities do these US engagements with human rights language reveal, and what lessons do they offer the health and human rights community more broadly?

Before summarizing the papers themselves, I provide a brief historical overview of American presidential administrations’ resistance to confronting health issues in a human rights idiom.

### Health and human rights in the United States: Legacies and missed opportunities

Under different circumstances, the vision of President Franklin Delano Roosevelt and human rights pioneer Eleanor Roosevelt might have propelled the United States to an enduring leadership role in refining and implementing international commitments to health as a human right. FDR’s 1941 “Four Freedoms” speech, for instance, introduced the notion that states are obligated to provide for the health of their people. On the domestic front, his 1944 State of the Union address called for a “second Bill of Rights” promising every American citizen the “right to adequate medical care and the opportunity to achieve and enjoy good health.”<sup>9</sup> Four years later, Eleanor Roosevelt represented the United States at the deliberations culminating in the 1948 Universal Declaration of Human Rights (UDHR), which affirmed that, “Everyone has the right to a standard of living adequate for the health

and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services.”<sup>10</sup>

Rather than carry this legacy forward, however, the United States retreated. During the Cold War, the world was divided—in effect, into countries rallying behind civil and political rights, led by the United States, and advocates of economic and social rights, led by the Soviet Union. This sharp distinction faded with decolonization and the end of the Cold War, and more than 150 countries have now ratified the International Covenant on Economic, Social Cultural Rights (ICESCR), although the United States still has not. Neither has the United States ratified most other international treaties that include a right to health commitment. Instead, successive American presidential administrations have sought to avoid incurring obligations relating to the right to health or other economic, social, and cultural rights, and the country has promoted a raft of neoliberal strategies in its foreign policy that push in the opposite direction.<sup>11</sup> Given its general unwillingness to join “with other countries in advancing and adhering to the international framework of human rights laws,” some human rights experts have characterized the United States as a “rogue state” in human rights terms.<sup>12</sup>

Meanwhile, on the domestic front, a variety of obstacles have impeded efforts since the 1940s to enshrine right to health commitments in US law.<sup>13</sup> These factors range widely, from the individualist approach to rights within the Anglo-American tradition to the resistance of powerful stakeholders (including the American Medical Association and the private health insurance industry); the rise of neoliberal economic policy under the Reagan administration; and the willingness of left-leaning Democrats to entertain market-based solutions to universal health coverage rather than pushing harder for a “single-payer” solution or “public option” during the ACA debates.<sup>14</sup> Despite strong legacies of civil society struggle against the egregious health disparities that persist in the United States even post-ACA, human rights claims have been invoked only infrequently by those commit-

ted to combating the country’s health inequities, and only with moderate, typically localized (such as state-level) success.<sup>15</sup> Although the notion that all Americans possess a basic human right to health may be gaining some popularity since the 2016 presidential election cycle, the impact of this shift on both national and local politics remains to be seen. For the time being, most struggles against health inequities in the United States employ other “idioms of social justice mobilization.”<sup>16</sup> Some of these idioms, like “health disparities” and the “social determinants of health,” aim for descriptive neutrality or scientific objectivity. Others, such as “health inequities” and, increasingly “structural racism,” involve built-in forms of political critique.

## Overview of the papers

The original catalyst for this special section was the aforementioned museum exhibition “Health Is a Human Right: Race and Place in America,” which was created to commemorate the 25th anniversary of the Office of Minority Health and Health Equity (OMHHE) at CDC. During the seven months it was on display at the Smithsonian-affiliated David J. Sencer Museum, located on CDC’s main campus in Atlanta, Georgia, the exhibition attracted nearly 50,000 visitors. The special section itself began as an invited panel at the 2016 American Anthropological Association Annual (AAA) Meetings in Minneapolis, Minnesota. Although the original panel included companion perspectives on the exhibition from its originators at CDC, the shifting political landscapes limited their inclusion in this section.

In the first paper, I examine the origins, aims, and content of the CDC Museum’s exhibition and the apparent contradiction it embodies. The paper asks three questions: First, how can this exhibition, in this particular locale, be reconciled—if at all—with the absence of any firm right to health commitment in the United States? Second, what does the exhibition reveal about the “social life” of health-related human rights claims? Finally, what might we learn from the exhibition about the potential role of museums and museology in sparking



public engagement with health and human rights issues, especially in settings where human rights have some rhetorical power, but lack legal or political traction?

The second paper, by Salhi and Brown, approaches the CDC museum exhibition from a different angle: exploring the reactions of university students who visited as part of a semester-long course on global health. Drawing on written student assessments and their own long-term teaching experience in American university settings, the authors describe the exhibition as a rude awakening for many students. In particular, many were surprised to discover a long history of health-related human rights violations within the United States, ranging from 20th century legacies of eugenics and forced sterilization, to systemic violations whose effects persist until today, including “redlining,” the dumping of toxic waste near residential communities, and lack of access to safe water and/or basic sanitation, especially among impoverished communities of color.<sup>17</sup> Student-visitors to the exhibition, the authors write, “displayed an intuitive sense of—and support for—certain human rights” even as they lacked “the vocabulary or framework to anchor these sentiments” and arrived “unaware that human rights are dynamic legal tools and principles that apply in regional, national, and international spheres.” The authors acknowledge the power of a well-curated exhibition to spark new thinking about health and human rights in two ways: by showing that health-related violations can, and do, happen on American soil, and by demonstrating the relevance of human rights laws and logic for domestic efforts to name injustices and mobilize for change.

Finally, Gaber’s paper addresses one of the exhibition themes of greatest concern to Salhi and Brown’s students: contemporary violations of the human right to water. Although 99% of US residents have safe access to drinking water and 89.5% have safe access to sanitation, water insecurity is increasingly a problem, not just for rural communities but also in urban settings.<sup>18</sup> Drawing on ethnographic fieldwork involving community-based participatory research (CBPR) projects in the cities of Flint and

Detroit, Michigan, Gaber argues that human rights frameworks are growing more important as citizens mobilize for water justice despite the lack of a human right to water under US law. In their efforts to “generate data in the absence of credible, public information about the water crises,” CBPR projects in Flint and Detroit show how health evidence can “play a unique role in protecting the human right to water ... by supporting ethical demands, policy recommendations, and local organizing efforts with robust, reliable data.” Moreover, Gaber shows how CBPR findings framed in a human rights idiom can influence how violations and questions of redress are debated in the court of public opinion. In all, her paper suggests an important role for CBPR in certain kinds of human rights claims-making in the United States, given its ability to bring community member voices, values, and demands into political and even legal conversations that presumed experts might otherwise dominate.

## Conclusion

As the first United Nations Special Rapporteur on the right to health Paul Hunt and colleagues have observed, there are many ways to assess “how human rights are making a difference for health.”<sup>19</sup> Certainly this assertion is true, and its meaning may be even broader than its authors originally intended. For those who fall on what Mark Goodale describes as the “establishment” side of the human rights enterprise, opportunities to help human rights make a difference are increasingly well-defined; these include strategies to improve the effectiveness of legal interventions; strengthen claims for institutional legitimacy; and develop clearer lines of accountability.<sup>20</sup> Goodale contrasts this “establishment” orientation with what he calls an “alternative” position espoused by those for whom “the status of human rights remains as ‘unsettled’ (Sarat & Kearns 2001) as ever.”<sup>21</sup> Although he and others in this “alternative” camp might remain “agnostic about the underlying value claims and political aspirations that ground existing human rights activism,” they are not inclined to abandon the human rights project altogether. Rather, they

see the need for a “reconfigured theory and practice of human rights that is pluralist, decentralized, and perhaps even ‘de-juridified.’”<sup>22</sup> Among other things, Goodale’s proposal for radical reconfiguration clarifies the extent to which human rights can, and do, travel meaningfully beyond spaces of law. In addition, it invites reflection on other ways in which human rights can make a difference for health—even in places where the “non-practice” of human rights is more common than its practice.<sup>23</sup>

In such places, non-specialist members of the public may have little or no understanding of what human rights entail, or how rights violations and health inequities are interconnected. This specialized language may someday catalyze new ways of thinking—but first, citizens and community members will need an introduction. Unconventional invocations of human rights like those explored in this special section—especially in museums and community-based participatory research settings—may effectively serve this role. By showing how human rights can be meaningful, timely, and relevant even in countries lacking formal human rights commitments, such informal encounters can spark creative thinking and help expand public imaginings of how human rights can make a difference for health.

## Acknowledgments

Earlier versions of the papers in this special section were presented as part of the Society for Medical Anthropology (SMA)/Society for the Anthropology of North America (SANA) Invited Session, “Health & Human Rights in the U.S.: Violations, Representations, Action,” at the 2016 American Anthropological Association Annual Meetings in Minneapolis, Minnesota, USA. The guest editor is grateful to Leandro Liburd, Louise Shaw, and César Abadía-Barrero for their valuable contributions to the original panel.

## References

1. B. M. Meier and L. Gable, “US efforts to realise the right to health through the Patient Protection and Affordable Care Act,” *Human Rights Law Review* 13/1 (2013), pp.

167–190.

2. D. Orentlicher, “Rights to healthcare in the United States: Inherently unstable,” *American Journal of Law & Medicine* 38 (2012), pp. 326–347.

3. Meier and Gable (see note 1).

4. See, e.g., Associated Press, “Sanders unveils bill, saying ‘health care is a human right,’” *New York Times*, April 10, 2019.

5. T. Destrooper, “Introduction: On travel, translation, and transformation,” in S. E. Merry and T. Destrooper (eds), *Human rights transformation in practice* (University of Pennsylvania Press, 2018); see also T. Basok, “Counter-hegemonic human rights discourses and migrant rights activism in the US and Canada,” *International Journal of Comparative Sociology* 50/2 (2009), pp. 183–205, as well as J. C. Carmalt, S. Zaidi, and A. E. Yamin, “Entrenched inequity: Health care in the United States,” in S. Hertel and K. Libal (eds), *Human rights in the United States: Beyond exceptionalism* (Cambridge University Press, 2011); K. S. Ratcliff, “Health and human rights,” in W. T. Armaline, D. S. Glasberg and B. Purkayastha (eds), *Human rights in our own backyard: Injustice and resistance in the United States* (University of Pennsylvania Press, 2011); M. McGill, “Human rights from the grassroots up: Vermont’s campaign for universal health care,” *Health and Human Rights: An International Journal* 14 (2012); G. MacNaughton, M. McGill, A. Jakubec, et al., “Engaging human rights norms to realize universal health care in Massachusetts, USA,” *Health and Human Rights Journal* 20/2 (2018).

6. S. S. Willen, M. Knipper, C. E. Abadía-Barrero, et al., “Syndemic vulnerability and the right to health,” *The Lancet* 389 (2017), pp. 964–977.

7. R. A. Wilson, *The politics of truth and reconciliation in South Africa: Legitimizing the post-apartheid state* (Cambridge University Press, 2001).

8. P. Levitt, and S. Merry, “Vernacularization on the ground: Local uses of global women’s rights in Peru, China, India and the United States,” *Global Networks* 9 (2009), pp. 441–461; M. Goodale, “Ethical theory as social practice,” *American Anthropologist* 108 (2006), pp. 25–37.

9. C. R. Sunstein, *The second bill of rights: FDR’s unfinished revolution and why we need it more than ever* (Basic Books, 2004); Meier and Gable (see note 1).

10. United Nations General Assembly, *Universal Declaration of Human Rights* (1948).

11. W. T. Armaline, D. S. Glasberg, and B. Purkayastha, *Human rights in our own backyard: Injustice and resistance in the United States* (University of Pennsylvania Press, 2011); S. Hertel, and K. Libal, *Human rights in the United States: Beyond exceptionalism* (Cambridge University Press, 2013); M. Basilio, J. Weigel, A. Motgi, et al., “Health for all? Competing theories and geopolitics,” in *Reimagining global health* (University of California Press, 2013), pp. 74–110.

12. J. R. Blau, D. L. Brunsma, A. Moncada, et al. (eds), *The leading rogue state: The United States and human rights*

(Routledge, 2008).

13. A. R. Chapman (ed), *Health care reform: A human rights approach* (Georgetown University Press, 1994); A. E. Yamin, "The right to health under international law and its relevance in the United States," *American Journal of Public Health* 95 (2005), pp. 1156–1161; R. D. Persaud, "Rights-based approaches and health disparities in the United States," in E. Beracochea, C. Weinstein and D. P. Evans (eds), *Rights-based approaches to public health* (Springer, 2011); Meier and Gable (see note 1); Meier and Gable (see note 1); Hertel and Libal (see note 11).

14. A. R. Chapman, "Introduction," in *Health care reform: A human rights approach* (Georgetown University Press, 1994); Meier and Gable (see note 1).

15. M. McGill, "Using human rights to move beyond the politically possible," *Clearinghouse Review* 44 (2010); A. Rudiger, and B. M. Meier, "A rights-based approach to health care reform," in Elvira Beracochea, Corey Weinstein and Dabney Evans (eds), *Rights based approaches to public health* (Springer, 2011); G. MacNaughton, and M. McGill, "Economic and social rights in the United States: Implementation without ratification," *Northeastern University Law Journal* 4 (2012); McGill (see note 5); MacNaughton et al (see note 5); Ratcliff (see note 5); Armaline et al (see note 11).

16. Willen et al (see note 6).

17. R. Rothstein, *The color of law: A forgotten history of how our government segregated America* (2017); Commission for Racial Justice, *Toxic wastes and race in the United States: A national report on the racial and socio-economic characteristics of communities with hazardous waste sites* (United Church of Christ, 1987); S. Gasteyer, and R. T. Vaswani, *Still living without the basics in the 21st century: Analyzing the availability of water and sanitation services in the United States* (Rural Community Assistance Partnership, 2004).

18. World Health Organization and UNICEF, "Progress on drinking water, sanitation and hygiene: 2015 update and MDG assessment," *WHO Press* (Geneva, 2015).

19. P. Hunt, A. E. Yamin, and F. Bustreo, "Making the case: What is the evidence of impact of applying human rights-based approaches to health?," *Health and Human Rights Journal* 17/2 (2015), pp. 1–9.

20. M. Goodale, "Afterword: Our vernacular futures," in T. Destrooper and S. E. Merry (eds), *Human rights transformation in practice* (University of Pennsylvania Press, 2019), pp. 251–262.

21. Ibid; A. Sarat, and T. R. Kearns, "The unsettled status of human rights," in A. Sarat and T. R. Kearns (eds), *Human rights: Concepts, contests, contingencies* (University of Michigan Press, 2001), pp. 1–24.

22. Ibid.

23. Ibid; E. Desmet, "Rural-urban migration and education in China: Unraveling responses to injurious experiences," in T. Destrooper and S. E. Merry (eds), *Human*

*rights transformation in practice* (University of Pennsylvania Press, 2019), pp. 183–207.

# Health Is a Human Right—at CDC?

SARAH S. WILLEN

## Abstract

In 2013–14, the Smithsonian-affiliated David J. Sencer Museum at the US Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia, hosted an original exhibition with an eye-catching title: “Health Is a Human Right: Race and Place in America.” Given the American government’s entrenched resistance to health-related human rights claims, the staging of an exhibition with this title at a museum described as the public face of CDC was striking. Taking this apparent disjuncture as point of departure, this article examines the origins, aims, and content of the “Health Is A Human Right” exhibition, which attracted nearly 50,000 visitors. Drawing on qualitative research findings, the article engages three interrelated questions: First, how can this exhibition, in this particular locale, be reconciled—if at all—with the absence of any firm right to health commitment in the United States? Second, what does the exhibition reveal about the “social life” of health-related human rights claims? Finally, what might we learn from the exhibition about the potential role of museums and museology in sparking public engagement with health and human rights issues, especially in settings where human rights have some rhetorical power but lack legal or political traction?

---

SARAH S. WILLEN, PhD, MPH, is an associate professor of anthropology and director of the Research Program on Global Health and Human Rights at the Human Rights Institute, University of Connecticut, Storrs, Connecticut, USA.

Please address correspondence to Sarah S. Willen. Email: sarah.willen@uconn.edu.

Competing interests: None declared.

Copyright © 2019 Willen. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted noncommercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

FIGURE 1. “Branding image” for the exhibition, featuring a 1947 photo of a racially/ethnically diverse elementary school class in San Francisco. (Unless otherwise noted, all images are courtesy of the David J. Sencer CDC Museum.)

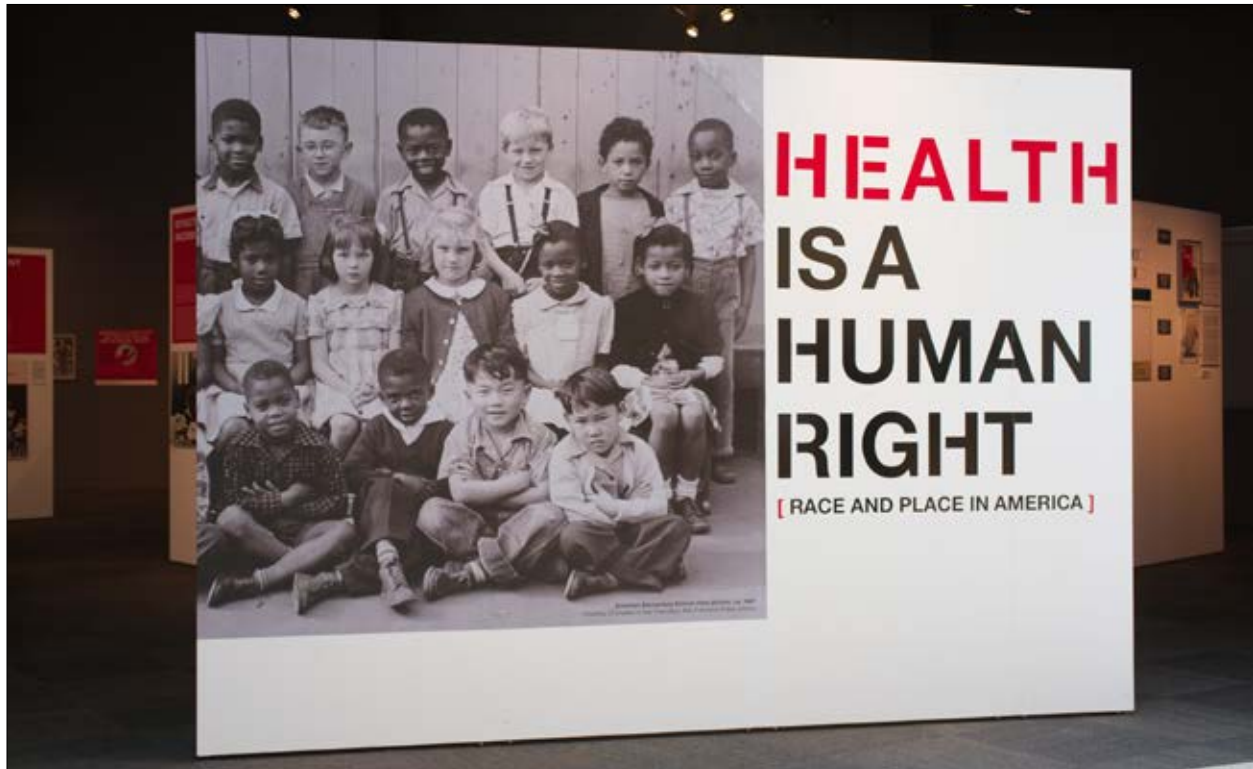


FIGURE 2. Entrance to the “Health Is a Human Right” exhibition.



## Introduction

In 2013-14, the Smithsonian-affiliated David J. Sencer Museum on the main campus of the United States Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia, hosted an original

exhibition with an eye-catching title, announced in bold in the opening panel: “Health Is a Human Right: Race and Place in America.” I learned of the exhibition purely by chance—by stumbling upon the website during a Google Search—in October 2013, a month after it launched. My response was a double-take: An exhibition called “Health Is a Human Right”—at CDC, the “nation’s premiere health promotion, prevention, and preparedness agency,” which operates under the federal Department of Health and Human Services?<sup>1</sup> A few clicks through the exhibition website confirmed there was no mistake. A major exhibition—designed to chronicle the enduring health impact of over a century of discriminatory laws, policies, and practices in the United States—had been launched to commemorate the 25<sup>th</sup> anniversary of CDC’s Office of Minority Health and Healthy Equity (OMHHE). It would be on display through spring 2014.

As a medical anthropologist with a long-standing interest in health and human rights, I



was intrigued—and perplexed. The staging of an exhibition with this title at the federally operated museum described as the “public face” of CDC was surprising in light of the US government’s deep resistance to human rights claims-making on American soil and the limited power of health-related human rights claims in American civil society more broadly.<sup>2</sup> In national debates about health care reform, for instance—including those culminating in the 2010 Affordable Care Act (ACA)—health and human rights claims had failed to gather much momentum.

In the following months, and with support from its CDC creators, an ethnographic study took shape with the exhibition as its focus. In this article, I triangulate among several forms of qualitative data gathered as part of that study to engage three interrelated questions. First, how can the exhibition’s title and location in a federal government museum be reconciled, if at all, with the absence of any firm right to health commitment on the part of the United States? Second, what does this exhibition reveal about what anthropologists describe as the “social life” of health-related human rights claims, including both the surprising routes through which human rights “travel” and their prominent role as a contemporary “idiom of social justice mobilization” for health?<sup>3</sup> Finally, what might we learn from this exhibition about the potential role of museums and museology in sparking public engagement with health and human rights issues, especially in settings where human rights have some rhetorical power but lack widespread legal or political traction?<sup>4</sup>

Before turning to the exhibition itself, let us first reflect briefly on its title and, in particular, on the fact that a US federal agency had created a major exhibition that pivoted, or at least appeared to pivot, on the claim that health is a human right. Almost 170 countries have ratified the International Covenant on Economic, Social and Cultural Rights (ICESCR), but the United States is not party to the ICESCR or most other international legal instruments in which a right to health is declared or defined. Neither is a right to health articulated in the US Constitution or federal law. Instead, successive presidential administrations have avoided

establishing obligations, domestic or global, in the realm of economic, social, and cultural rights.<sup>5</sup> Moreover, the United States has a long history of advancing laws and policies that commoditize health care and privatize its provision. Globally, it has promoted these neoliberal strategies in foreign policy and through its role in international institutions like the World Bank and the International Monetary Fund.<sup>6</sup> Civil society actors in the United States have found it difficult to stake health-related human rights claims, although the appeal of right to health claims has broadened among politically liberal segments of the American public since the 2016 presidential election cycle.<sup>7</sup> Overall, however, the American government, and society more broadly, have yet to reckon fully with the country’s long history of health-related human rights violations against citizens and others.<sup>8</sup>

Against this backdrop, the launch of an exhibition titled, “Health Is a Human Right” at a federal museum—a well-situated venue that welcomes approximately 95,000 visitors per year, as the curator told me—raises multiple questions. Why would OMHHE choose to frame their commemorative anniversary exhibition in this way? How did the theme of human rights find expression in the exhibition? Who was the intended audience, and what response did it garner—either internally, at CDC, or from other members of the visiting public? With these questions in mind, the first aim of this article is to document and reflect on the exhibition’s origins, design, content, and objectives.

The article also has a second aim: to consider the power, and the limits, of a health and human rights framework for catalyzing discussion about health, history, and inequity in the United States. In pursuing this aim, I draw on the interdisciplinary tradition of critical human rights scholarship, which takes strong cues from anthropology and attends carefully to what Richard Wilson calls the “social life of rights.”<sup>9</sup> From a “social life of rights” standpoint, the title and exhibition offer a unique opportunity to consider how human rights can “travel” far from their juridical origins and play new roles in distinctly non-legal settings.<sup>10</sup> As Tine Destrooper puts it, “human rights can no longer be

considered merely as a matter of international law (if this was indeed ever possible); rather, “there is a wide range of ways in which to employ human rights, from the use of human rights language as a tool for explicit and formal mobilization to the invocation of human rights values without direct reference to their legal and institutional grounding.”<sup>11</sup> This orientation helps clarify both the tension and the power invoked by the exhibition’s titular claim that “health is a human right.” Rather than testing the strength or validity of such a claim in legal terms, a “social life of rights” perspective instead invites recognition that this claim is a tool that can be deployed, to different ends, by different stakeholders.

Specifically, this approach invites us to consider how the claim that “health is a human right” can function as what I describe elsewhere as an “idiom of social justice mobilization” for health: a model, or framework, for thinking about the relationship between health and (in)justice.<sup>12</sup> The term “idiom” evokes a language—a mutually accessible way of organizing thought and consolidating interest and commitment. Arguably, some fields of research, scholarship, and practice themselves function as idioms of social justice mobilization for health: social medicine, social epidemiology, medical humanitarianism, and global health come to mind. Other idioms can better be described as models or conceptual frameworks, including the social determinants of health, the notion of health equity, the concept of structural racism, and claims of a human right to health. Alongside these disciplinary and conceptual idioms are another sort: idioms that emerge at a particular historical moment and function as “branded strateg[ies] for advancing a particular set of ethical or political commitments.”<sup>13</sup> Examples include the Alma-Ata commitment to “Health for all by the Year 2000,” the World Health Organization’s “3 by 5 Initiative,” and the United Nations’ “Millennium Development Goals.”

From a critical human rights standpoint, these diverse idioms of social justice mobilization for health are far more than just “buzzwords.”<sup>14</sup> Each is a powerful—and distinct—conceptual framework with its own genealogy, disciplinary orientation,

and community of practice. Each takes a different tack in trying to debunk claims that health disparities are somehow “natural” or beyond the scope of human intervention. And each strives to catalyze a somewhat different kind of action. Although different idioms of social justice mobilization stand in variable relation to one another, they often are invoked together—including, at times, with other idioms that stem from very different disciplines, espouse different core principles, and advance different strategic aims.

As the CDC Museum’s exhibition clearly demonstrates, idioms of social justice mobilization seldom stand alone. Rather, different idioms—for instance, health equity, structural racism, social determinants of health, and the notion of a right to health—can travel together, at times complementing and clarifying one another, at other times in clear tension. When viewed through this lens, the exhibition provides an opportunity to reflect critically on the conceptual and discursive challenges of using human rights to frame conversations around health and justice in a world riven by economic inequality, political instability, and deficient leadership—especially, but by no means exclusively, in the United States.

In what follows, I begin with a brief discussion of research methods, then turn to the larger story of the exhibition, including its roots in OMMHE. I include photographs to give readers a glimpse into visitors’ experience and a sense of the exhibition’s size and scope. In concluding, I return to the article’s opening questions about how the claim that “health is a human right” can become untethered from law and juridical practice and function, instead, in the social realm—as an idiom for social justice mobilization for health. The article closes with a brief discussion of lessons we can learn from this unique exhibition about the role museums and museology might play in catalyzing public engagement with matters of health and human rights concern.

## Research methods

This article draws on findings from an ethnographic study of the CDC Museum’s “Health Is a Human

Right” exhibition, located in CDC’s secure federal facility in Atlanta, Georgia. Research methods included (1) three tours of the exhibition, including one curator-guided tour; (2) semi-structured interviews and multiple informal conversations with the chief architects of the exhibition—the director of OMHHE and the Sencer Museum curator—as well as other CDC staff; and (3) semi-structured interviews with two university faculty who required their students to visit the exhibition. Interviews were audio recorded, transcribed, and analyzed using the Dedoose qualitative software platform. Additional resources accessed include (4) worksheets used by the curator and her team to develop the exhibition panels; (5) the accompanying exhibition text (80 single-spaced pages); (6) audio-visual records of the exhibition, including photographs and videos; and (7) the transcript of an online discussion on a CDC staff listserv that was prompted by the exhibition.

In addition, I have followed the exhibition into its second (physical) and third (online) iterations. In 2017, CDC took the first-ever step of gifting portions of exhibition material to Georgia State University, also in Atlanta, which modified it for display at the university’s school of public health. The Georgia State library also created a condensed version that is accessible online.<sup>15</sup>

This study was deemed exempt by the Institutional Review Board at the University of Connecticut.

### A celebratory exhibition

“Health Is a Human Right: Race and Place in America” was created to commemorate the 25<sup>th</sup> anniversary of OMHHE, an office established in 1988 in direct response to a 1985 landmark report issued by the US Department of Health and Human Services (HHS): the Report of the secretary’s task force on black and

minority health, commonly known as the Heckler Report.<sup>16</sup> The origins of the report, and of OMHHE, illuminate the complex ways in which science, politics, and personal values can become entangled in a manner that directly affects health policy and, ultimately, population health.

When Margaret Heckler was appointed secretary of Health and Human Services by President Ronald Reagan in 1983, the Republican from Massachusetts had no experience in public health. The impact of the eight-volume report she commissioned during her tenure, however, would be difficult to overstate. First, the Heckler Report offered the first formal recognition from HHS that vast and deep-rooted population-level health disparities exist in the United States, noting that each year, African Americans suffer 60,000 excess deaths relative to the US population as a whole. In her foreword to the volume, Heckler describes this as “a sad and significant fact.” She continues:

*I felt—passionately—that it was time to decipher the message inherent in that disparity. In order to unravel the complex picture provided by our data and experience, I established a Secretarial Task Force whose broad assignment was the comprehensive investigation of the health problems*

FIGURE 3. Opening panel of the “Health Is a Human Right” exhibition. The cover of the Heckler Report is displayed on the far left, accompanied by definitions of the exhibition’s core concepts (center).



*of Blacks, Native Americans, Hispanics and Asian/Pacific Islanders.*<sup>17</sup>

In effect, the Heckler Report explicitly defined health disparities as what would be described in early 21<sup>st</sup> century terms as “inequities”—in other words, as differences that are not simply “unnecessary and avoidable,” but “also considered unfair and unjust.”<sup>18</sup> In the decades that followed its publication, the Heckler Report became widely recognized as “a transformative, driving force for change” not simply because of its innovative science, but also because of the way it put epidemiology and public health to work in the service of ethical aims. As one national public health leader put it, the report

*influenced many milestones in the health equity movement: pivotal legislation, funding, policies, research, and initiatives focused on minority health and health equity; establishment of offices of minority health within NIH, the Centers for Disease Control and Prevention, and the Health Resources and Services Administration; more inclusive data collection techniques; dedicated institutions, centers, commissions, and state, territorial, and local offices of minority health across the country; and innovative community-level interventions.*<sup>19</sup>

The establishment of the Office of Minority Health at CDC in 1988—an office whose mandate was expanded in 2011 to include health equity and again in 2018 to include women’s health—was thus one direct outcome of the Heckler Report.<sup>20</sup> Now identified as OMHHE, its mission is to “Advance health equity and women’s health issues across the nation through CDC’s science and programs, and increase CDC’s capacity to leverage its diverse workforce and engage stakeholders toward this end.”<sup>21</sup>

Despite the Heckler Report’s resounding impact, critics saw it as a missed opportunity to define these newly documented disparities as violations of human rights. In fact, doing so would have been foreign to Heckler, whose keynote at the first International AIDS Conference in Atlanta in 1985 could not be described as comporting with human rights principles. In a departure from her prepared speech, Heckler told the assembled gathering: “We must conquer AIDS before it affects the heterosex-

ual population and the general population.... We have a very strong public interest in stopping AIDS before it spreads outside the risk groups, before it becomes an overwhelming problem.”<sup>22</sup>

### *The making of the exhibition*

The 25th anniversary of OMHHE, the director explained in a 2014 interview, was an important occasion to celebrate, both at CDC and for the broader public. As such, it was a key opportunity to partner with the David J. Sencer Museum, which was created in 1996 and later named to honor the agency’s longest serving director.

The museum is both accessible (after passing through a security checkpoint) and free to the public, and its 5,000 square-foot, two-level gallery is immediately visible to anyone arriving at the agency’s main entrance. The lower level contains a permanent exhibit about the history of CDC. The much larger, entry-level gallery hosts temporary exhibitions on topics ranging from specific diseases like cancer and Ebola, to vulnerable communities like refugees and physical laborers (in mining, fishing, agriculture, construction, and other industries), to more conceptual themes, such as the relationship between art and science.<sup>23</sup> Some are visiting exhibitions, while others are created at CDC, but all use museological strategies to invite reflection on issues of social, medical, scientific, and moral concern. As the curator explained to me, the museum’s estimated 95,000 visitors per

FIGURE 4. Entrance to the CDC main campus in Atlanta, Georgia. The David J. Sencer CDC Museum occupies a large section of the building on the left.





FIGURE 5. Panel on structural racism. Key elements include an image of sociologist W.E.B. Dubois (far left), the cover of Dubois's 1906 book *The health and physique of the Negro American*, and Dubois's quote about Americans' "peculiar indifference" to the health of black Americans (in red on the right side of the panel, displayed above a photograph from a 1946 protest against discriminatory housing policies in Los Angeles).



year, including nearly 50,000 to this exhibition, are diverse, including CDC staff, visiting public health professionals and experts, students, and members of the general public. "We get a lot of people that are just fascinated by CDC," she explained. These include leisure travelers who tour the United States by RV [recreational vehicle] and, in recent years, visitors interested in *The Walking Dead*—a television series with scenes set at CDC headquarters.

Although different in some ways from its other exhibitions, "Health Is A Human Right" was consistent with the Sencer Museum's mission as the "public face" of CDC. According to the OMHHE director, it sought to counter the commonly held but mistaken view "that health disparities, particularly racial and ethnic health disparities, are intractable, or resistant to change."<sup>24</sup> She noted that strong evidence to the contrary had existed for well over a century and pointed, in particular, to the work of sociologist W.E.B. Dubois, whom I heard the curator describe on an exhibition tour as "the grandfather of the social determinants of health." As early as 1899, Dubois expressed public dismay over the "peculiar indifference" displayed by those

in power toward black Americans.<sup>25</sup> In a 1906 passage displayed prominently in the exhibition (see Figure 5), he made the strong claim that, "With improved sanitary conditions, improved education, and better economic opportunities, the mortality of the [black] race may and probably will steadily decrease until it becomes normal."<sup>26</sup> While guiding

FIGURE 6. The exhibition's section on economic opportunity highlighted historical moments of collective mobilization and activist effort, including the Memphis Sanitation Strike and the Poor People's March, both in 1968.





a tour, the curator asked for a volunteer to read this quotation aloud.

Not unlike Dubois, who brought sociological insight to bear in critiquing racial injustices in health in his own day, the OMHHE director anchored her vision in her training as both a public health professional and an anthropologist. Her declared goals for the exhibition were to (1) clarify for visitors the root causes of health disparities; (2) put disparities into historical context; and (3) “put a face on the data” in order to help data-oriented public health professionals and community members stretch their imaginations and “really see what those disparities look like.” She also wanted to recognize the work of advocates and activists who struggle to protect themselves and their communities, especially communities marginalized and impoverished as a result of political and policy decisions. By drawing attention to activist struggles, including struggles against powerful elites, corporate entities, and even government officials, she hoped the exhibition would “dispel the idea that people facing disadvantage don’t care” about the poor conditions and concomitant health risks they endure. The final aim of the exhibition, she explained, was to “show visually how much work needs to be done” before the goals of her office will be achieved.

As federal government employees, the chief architects of the exhibition—namely, the director of OMHHE and the Sencer Museum curator—faced

FIGURE 7. Display case showing a “Health Care Is a Human Right!” poster from a 1995 march across San Francisco’s Golden Gate Bridge.



challenges that differ markedly from those faced by most health and human rights advocates. In particular, they grappled with the best way to reflect on raw and painful episodes in recent history “in a very responsible but pointed way ... in a way that is mobilizing, that is, that’s not divisive.”

Even in 2013, when the exhibition launched, this was a tall order. Congress had passed the Obama administration’s ACA by a razor-thin majority in 2010. When implementation began in 2014, the heated national debate was ongoing. In that moment, when arguing about access to health care was highly divisive, the director saw the exhibition as an important opportunity to call attention to the broad conditions that support health, on one hand, while avoiding debates about health care, which the ACA continued to treat as a commodity, on the other. In keeping with these goals, the exhibition approached health in a manner that extended well beyond questions of access to care. It explored the enduring impact of policy decisions on population health; the historical intertwinement of policy sectors; and watershed moments in which advocacy and activist efforts sparked new conversations, laws, ways of thinking about evidence, and modes of political action. By juxtaposing visual representations of data with photographs, videos, interactive touch screens, artifacts, and art, the exhibition historicized key events and humanized population-level processes in an effort to bring them alive for visitors. Civil rights struggles were front and center. Beyond the title and opening panel, the claim that health (care) is a human right appeared just once, on a poster for a 1995 march across the Golden Gate Bridge in San Francisco (Figure 7). The closest the exhibition came to staking a human rights claim involved an aspirational statement in the closing panel: “Restricted access to the conditions needed for health is a human rights issue—one that has characterized the past, but doesn’t have to be repeated in the future.”

### *Health, rights, and museology*

The photographs included here cannot convey the detail, aesthetics, or multimedia dimensions of a major museum exhibition like this one. Nonetheless,

they suggest the choices and decisions of the curator and her working group as they sought to render OMHHE's vision both engaging and accessible.

Although the exhibition's core vision and major funding came from OMHHE, with support from the California Endowment, the design and content were in the hands of the curator, who has curated the museum's temporary and permanent exhibitions since 2002. Unlike most of her colleagues, she did not come to CDC with a background in public health. Trained in musicology, museum studies, and museology, she has worked as an art and history curator throughout her long career. She and a team of "subject matter experts" spent two years conducting research, planning the exhibition, and obtaining artifacts and permissions. For her, the main goal of the exhibition was "to connect the dots between the social determinants of health and health outcomes."

*Where people live, and work, and how much money they make, and environmental justice, and their education, and last but not least access to health care, that is all critical to health outcomes. ... [I]f nothing else, I wanted people from this exhibition to really understand those linkages.*

She decided that the best way to convey these interconnections was to organize exhibit sections around different social determinants of health.

Figure 8 lists the themes and historical episodes represented in the exhibition's 20 panels, which concentrated on 20th century events. The opening panels introduced and defined key terms and concepts like "health equity," the "social determinants of health," and "structural racism,"

and demonstrated their relevance using visual representations and historical artifacts. Notably, the "right to health" was not among them, nor did the exhibit reference any fundamental health and human rights documents such as the UDHR, ICE-SCR, or General Comment 14.

From the curator's perspective, another early panel—"Data=Evidence"—was vital. She explained: "[In] public health, and this has been drummed into me since I've been at CDC, if you can't measure the problem, you can't come up with solutions ... Everything at CDC and public health is data driven and it's evidence driven." To assimilate the exhibition's visual content and understand CDC's role, she explained, visitors would need a basic familiarity with principles of scientific research and evidence.

Although some issues received less attention than she would have liked—disability, for instance, and the experiences of LGBT Americans—the curator was generally pleased with the way the exhibition came together, especially with the "branding" image that greeted in-person and online visitors to the exhibition: a 1947 black-and-white photograph of a racially/ethnically diverse elementary school class in San Francisco (Figure 1). She explained:

*It's really important as an art curator, doing history, to develop visually impactful exhibitions. Most visitors won't read much of the text, so we depend on visual strategies to tell the stories we want to convey. Case in point is Health Is a Human Right. You saw the text. I had no expectation anybody would come into this gallery and read all of it.*

FIGURE 8. Exhibition panel themes

Health Is a Human Right: Race and Place in America	
Data = Evidence	Food equity
Place matters	Environmental rights
Structural racism	Education
Experimentation	Access to health care
A nation of immigrants	Case study: Tuberculosis
Displacement	Case study: Type II diabetes
Economic opportunity	HIV/AIDS in minority communities
Housing, community, and transportation	AIDS in the 21st century
Sanitation	What does the future hold?
Activism	

To transcend the limitations of text, she chose a striking, memorable image laden with historical and moral meaning. This image oriented visitors to a vision of the United States as a land of diversity, past, present, and future, she explained, and it exemplified the exhibition's overarching moral message:

*At the end of the day, it's the children we need to care about because they represent the future. In just a few years, the United States is going to be a majority-minority country. Not only is addressing health inequities the moral thing to do, but it's also the practical thing to do.*

As the curator's comments make clear, creating a museum exhibition like this one involves striking a balance between aesthetic, professional, and institutional considerations, as well as moral ones. To understand the design of the exhibition and its title, we need to keep in mind the role of the curator and the curatorial logic at play.

FIGURE 9. 1977 poster by Rachel Romero announcing a public hearing about the forced sterilization of Latina women.



### *Guiding themes: Human rights violations and the power of collective action*

Two key themes were especially prominent. First, although its title claim was not elaborated in the panels themselves, the resonance between health-related human rights violations and the exhibition's content and framing concepts—"health equity," "social

FIGURE 10. This display case, located centrally in the exhibition hall, contained a corroded water pipe and contaminated tap water samples from the San Joaquin Valley, California.



determinants of health," and "structural racism"—was unmistakable. Indeed, the exhibition was full of concrete evidence of specific instances that can be and have been described as human rights violations:

- the forced sterilization of women, many of them poor, institutionalized, and/or people of color;
- the forced relocation of American Indians from their tribal lands;
- the forced relocation of African American sharecroppers in the South;
- the internment of Japanese Americans during the Second World War; and
- medical experiments on vulnerable populations both before and after the Second World War atrocities litigated at Nuremberg, including the US Public Health Service Syphilis Study at Tuskegee, as well as the testing of isoniazid, an antibiotic developed to treat tuberculosis, on members of the Navajo nation.

Another section, on sanitation, noted that, "Today more than 639,000 households lack indoor plumbing," and that some people—many of them in "rural and urban communities in Alaska, southern California, rural areas of Appalachia, the *colonias* along the US-Mexico border, U.S. territories, and Indian reservations"—still lack access to water that is reli-



FIGURE 11. Enlarged version of the 1991 ACT UP postcard sent to James Curran, who was then serving as Director of CDC's HIV/AIDS Task Force.



ably safe and drinkable. Notably, the exhibition had been open to the public for more than six months on April 25, 2014—the date on which officials in Flint, Michigan, announced the city had switched its water supply from the city of Detroit to the Flint River, a decision that catalyzed a slow-moving catastrophe that continues to damage the city's infrastructure, economy, and residents' health.<sup>27</sup>

The exhibition involved a second central theme as well: It called attention to cases in which activists achieved change by exerting pressure on powerful actors and institutions. Exhibition panels highlighted a number of mid-century activist ef-

FIGURE 12. Postcards sent in 1991 to James Curran, who was then serving as director of CDC's HIV/AIDS Task Force, by the grassroots activist group ACT UP, accompanied by flyers publicizing ACT UP gatherings. (Photo by the author)



forts, including the Memphis Sanitation Strike and the Poor People's March, both of which took place in 1968. More recent movements were also featured, including a 1990-91 campaign by the AIDS activist group ACT UP. Founded in 1987 in New York, ACT UP, or the AIDS Coalition to Unleash Power, emerged as the AIDS crisis was devastating the US gay population, and before much was known about the disease. Strikingly, this section of the exhibition documents action taken by activists against CDC itself. The campaign's signature image—of James Curran, who then served as head of CDC's HIV/AIDS Task Force, beneath a red and white bullseye—was virtually impossible to miss. A caption explained:

*In December 1990, ACT UP took on CDC when it staged a protest outside of the agency's headquarters. The key issue: expansion of the case definition of AIDS to include infections specific to women and others. After the CDC protest in Atlanta, ACT UP relentlessly continued its actions, including sending 20,000 graphic postcards to Dr. James Curran, CDC's HIV/AIDS Task Force Director [in 1991]. In 1993, once the data supported the change, CDC did expand the case definition of AIDS to reflect the fuller spectrum of the disease.*

The panel text ends with requisite deference toward CDC's reigning epistemology—that is, the impossibility of changing a case definition, or shifting the flow of resources, without rigorous scientific evidence—but it tells a very different story as well. The urgency and terror of the unfolding AIDS crisis may be receding into historical memory, but the impact of the epidemic on the gay community in the 1980s and 1990s is difficult to overstate. The inclusion of this controversial instance of AIDS activism nods toward the extraordinary impact of the AIDS epidemic, and the vital role of LGBT activists, in catalyzing the health and human rights movement that exists today.<sup>28</sup>

From a museological standpoint, it made sense to highlight the role of grassroots and civil society activism in pushing leaders to focus on the disease. Given CDC's central role in shaping HIV research and policy both in the United States and globally, it also made sense to display material evidence of the

ACT UP campaign. Yet these goals could have been achieved quietly, for instance simply by putting campaign postcards or flyers on display (see Figure 12). The exhibition went several steps further. By giving a blown-up image of the controversial postcard central billing in the final section of the exhibition, and by contextualizing it with a passage about the tenaciousness and temerity of ACT UP activists, it conveyed another message as well: CDC is the government, and its authority is rooted in science, evidence, and power. And CDC, like the other US government agencies, is both fallible and amenable to change—including, at times, change driven by grassroots collective action.

No part of this message was cast in human rights terms. At the same time, it is consistent with both the spirit and the letter of core human rights commitments, including the right to participation and a raft of other rights enumerated in the UDHR and other key covenants and treaties.

## Conclusion

In this article, I have pursued three questions and close by addressing each in turn. First, how might museums and museology spark public engagement with health and human rights issues, especially in settings where human rights hold some rhetorical power, but lack legal or political traction? As this exhibition shows, museums—especially those that use multimedia such as audio, video, interactive touch screens, and historical artifacts—are able to marshal visual and aesthetic resources that remain inaccessible to those who typically read, and write for, journals like this one. Museum exhibitions can introduce instances of health-related human rights violation, and instances of collective action and activism, to large audiences spanning different ages, life stages, and educational levels. Of course, such efforts require heavy investments of time, research, money, and human effort. They also demand the requisite professional skills, including an acute sense of visual literacy and a recognition that textual explanation is both necessary and limited in its potential impact. As more museums take up human rights concepts and themes—among them

the National Center for Civil and Human Rights in Atlanta and the Canadian Museum for Human Rights in Winnipeg—it will be illuminating to reflect comparatively on the range of available tools, strategies, and successes. Yet such comparative efforts may be limited by museums' inability to systematically gather visitor reactions and feedback, as they are at the Sencer Museum.<sup>29</sup> Here, ethnographic research into the impact of such exhibitions and institutions may prove illuminating.

Second, what happens when we approach the assertion that health is a human right not simply as a juridical claim, but as a proposition with a “social life” of its own? As I propose elsewhere, the right to health should be explored ethnographically, “in all its guises: as a legal instrument, a social object, a rhetorical flourish, a node of contingent and precarious political consensus, a framework for translating theory into practice, and, finally ... a contemporary idiom of social justice mobilization.”<sup>30</sup> Many of these uses stand in tension with human rights claims rooted in legal instruments and juridical norms. For some health and human rights advocates, such non-juridical invocations are problematic. One of the Atlanta-based health and human rights experts I interviewed wondered before viewing the exhibition about the “elephant in the room”—that is, “how is the US government going to talk about health as a human right” given the “official party line ... that we do not believe that such a thing ... exists?” The exhibition's inattention to “anything that anybody that has a human rights background would expect to see,” including relevant “international covenants, conventions, and treaties and monitoring bodies, and reporting mechanisms,” was described as troubling. Another expert noted after visiting the exhibition that it “doesn't really help in terms of understanding the health and human rights linkage,” adding that “it's okay” because “it reflects well on CDC just to have that title, and to let people know that CDC is interested in human rights.”

Whether the latter interpretation held sway among CDC staff is another question altogether. Soon after the exhibition launched, a heated, mostly anonymous debate unfolded on an internal



CDC listserv in a tone that ranged from didactic, to funny, to caustic. In this online discussion, which involved approximately 15 participants (and which I was able to review some months later as a printed PDF), the exhibition itself went largely unmentioned. Central topics of debate included the new ACA legislation; proposals to redistribute wealth and associated political and ethical dilemmas; and the relevance of individual behavior and personal choice to health. Another topic of discussion involved the fundamental question prompted by the exhibition title: “Is health a human right?” Some participants in the online debate argued strongly in favor, while others took either a more ambivalent or an opposing stance. Two points were especially clear in this online conversation. First, CDC personnel hold divergent views on whether or not health is a human right. Second, it is not clear that the exhibition changed many minds. In short, the listserv debate reflected the fact that individual government agencies, like governments themselves, are not monoliths. Rather, they are comprised of individual people who hold a range of ideological positions.

This brings us to our third and final question: How can this exhibition, in this locale, be reconciled with the lack of any firm right to health commitment in the United States? From a juridical standpoint, it cannot. The exhibition “went through all of the reviews and clearances,” the OMHHE director explained, yet “it’s nothing that anyone expected to see at the CDC.” Despite the title’s lack of legal grounding, and despite clear differences among CDC staff, the exhibition’s architects reported a strong, intuitive sense of congruence between the title and their professional aims to educate and inspire. The title’s insistence that “health is a human right” shows precisely how this claim can function as an idiom of social justice mobilization alongside, albeit in tension with, other idioms such as “health equity” and the “social determinants of health.” Perhaps the strongest evidence for this insight lies in a 2013 conversation between the curator and Michael Marmot, who chaired the WHO Special Commission on the Social Determinants of Health, and who has avoided framing his own

goals in human rights terms—and, in so doing, has sparked a fair amount of controversy.<sup>31</sup> The curator recounted their conversation during his visit to the exhibition, delighting in his positive feedback: “You talk about human rights, then don’t bring it up again,” she remembered him saying. He continued: “I would have done the same.”

## Acknowledgments

Thanks are due to the Human Rights Institute at the University of Connecticut for research support, to Dr. Leandris Liburd and Louise Shaw for facilitating the research that produced this essay, and to two anonymous reviewers for their critical feedback. An earlier version of this piece was presented to the Working Group on Anthropology and Population in the Department of Anthropology at Brown University.

## References

1. Centers for Disease Control and Prevention, *Our History - Our Story*. Available at <https://www.cdc.gov/about/history/index.html>.
2. CDC David J. Sencer Museum, *About the David J. Sencer CDC Museum*. Available at <https://www.cdc.gov/museum/about.htm>.
3. R. A. Wilson, “Afterword to ‘Anthropology and human rights in a new key’: The social life of human rights,” *American Anthropologist* 108 (2006), pp. 77–83; S. E. Merry, “Preface,” in T. Destrooper and S. E. Merry (eds), *Human rights transformation in practice* (University of Pennsylvania Press, 2018); S. S. Willen, M. Knipper, C. E. Abadía-Barrero, et al., “Syndemic vulnerability and the right to health,” *The Lancet* 389 (2017), pp. 964–977.
4. G. MacNaughton, M. McGill, A. Jakubec, et al., “Engaging human rights norms to realize universal health care in Massachusetts, USA,” *Health and Human Rights Journal* 20/2 (2018); M. McGill, “Human rights from the grassroots up: Vermont’s campaign for universal health care,” *Health and Human Rights: An International Journal* 14 (2012); A. C. Finnegan, and S. K. White, “Vermont and healthcare reform organizing: Human rights promise and praxis,” *Journal of Human Rights Practice* 8/1 (2016), pp. 148–170.
5. W. T. Armaline, D. S. Glasberg, and B. Purkayastha, *Human rights in our own backyard: Injustice and resistance in the United States* (University of Pennsylvania Press, 2011); S. Hertel, and K. Libal, *Human rights in the United States: Beyond exceptionalism* (Cambridge University Press, 2013).

6. M. Basílico, J. Weigel, A. Motgi, et al., "Health for all? Competing theories and geopolitics," in *Reimagining global health* (University of California Press, 2013), pp. 74–110.
7. McGill (see note 6); G. MacNaughton, and M. McGill, "Economic and social rights in the United States: Implementation without ratification," *Northeastern University Law Journal* 4 (2012), p. 365; Associated Press, "Sanders unveils bill, saying 'health care is a human right,'" *New York Times*, April 10, 2019.
8. J. C. Carmalt, S. Zaidi, and A. E. Yamin, "Entrenched inequity: Health care in the United States," in S. Hertel and K. Libal (eds), *Human rights in the United States: Beyond exceptionalism* (Cambridge University Press, 2011); A. M. Brandt, "Racism and research: The case of the Tuskegee syphilis study," *The Hastings Center Report* 8/6 (1978), pp. 21–29; S. M. Reverby, "Listening to narratives from the Tuskegee syphilis study," *The Lancet* 377/9778 (2011), pp. 1646–1647; S. Reverby, "Reflections on apologies and the studies in Tuskegee and Guatemala," *Ethics & Behavior* 22 (2012), pp. 493–495; K. S. Ratcliff, "Health and human rights," in W. T. Armaline, D. S. Glasberg and B. Purkayastha (eds), *Human rights in our own backyard: Injustice and resistance in the United States* (University of Pennsylvania Press, 2011); N. L. Novak, N. Lira, K. E. O'Connor, et al., "Disproportionate sterilization of Latinos under California's eugenic sterilization program, 1920–1945," *American Journal of Public Health* 108/5 (2018), pp. 611–613; A. Stubblefield, "Beyond the pale: Tainted whiteness, cognitive disability, and eugenic sterilization," *Hypatia* 22/2 (2007), pp. 162–181.
9. R. Wilson (see note 3); S. S. Willen, "Do 'illegal' migrants have a 'right to health'? Engaging ethical theory as social practice at a Tel Aviv open clinic," *Medical Anthropology Quarterly* 25/3 (2011), pp. 303–330.
10. S. E. Merry (see note 3). R. A. Wilson, and J. P. Mitchell, "Introduction: The social life of rights," in R. A. Wilson and J. P. Mitchell (eds), *Human rights in global perspective: Anthropological studies of rights, claims, and entitlements* (Routledge, 2003); W. T. Armaline, D. S. Glasberg, and B. Purkayastha, *The human rights enterprise: Political sociology, state power, and social movements*. (Wiley, 2015); M. Goodale, "Toward a critical anthropology of human rights," *Current Anthropology* 47 (2006), pp. 485–511; T. Destrooper, and S. E. Merry (eds), *Human rights transformation in practice* (University of Pennsylvania Press, 2018), p. 278.
11. T. Destrooper, "Introduction: On Travel, Translation, and Transformation," in S. E. Merry and T. Destrooper (eds), *Human rights transformation in practice* (University of Pennsylvania Press, 2018), p. 2.
12. Willen et al (see note 3); Willen (see note 11); S. S. Willen, *Fighting for dignity: Migrant lives at Israel's margins* (University of Pennsylvania Press, forthcoming 2019).
13. Willen (see note 11), p. 306.
14. A. Cornwall and K. Brock, "What do buzzwords do for development policy? A critical look at 'participation,' 'empowerment' and 'poverty reduction,'" *Third World Quarterly* 26/7 (2005), pp. 1043–1060; A. Cornwall, "Buzzwords and fuzzwords: Deconstructing development discourse," *Development in Practice* 17/4–5 (2007), pp. 471–484; A. Rosenthal, "Weaving networks of responsibility: Community work in development programs in rural Malawi," *Medical Anthropology* 31/5 (2012), pp. 420–437.
15. Available at <https://exhibits.library.gsu.edu/current/exhibits/show/health-is-a-human-right/introduction-to-the-exhibit>; see also K. Ramsey-White, "Remarks at launch event for 'Health Is a Human Right: Race and Place in America' at Georgia State University" (2017).
16. Department of Health and Human Services, Report of the secretary's task force on black and minority health (the Heckler Report) (DHHS, 1985).
17. M. Heckler, "Secretary's forward and charge to the task force," in Report of the secretary's task force on black and minority health, Volume 1 ((DHHS, 1985).
18. M. Whitehead, "The concepts and principles of equity and health," *International Journal of Health Services* 22/3 (1992), pp. 429–445.
19. J. N. Gracia, "Remembering Margaret Heckler's commitment to advancing minority health," *Health Affairs Blog*, 2018.
20. Office of Minority Health & Health Equity, Centers for Disease Control and Prevention, "Selected achievements and milestones in CDC's Office of Minority Health and Health Equity. May 18," 2018.
21. Office of Minority Health & Health Equity, Centers for Disease Control and Prevention, "Mission, Vision, Goals," 2019.
22. R. Shilts, *And the band played on: Politics, people, and the AIDS epidemic* (St. Martin's Griffin, 2000), p. 554.
23. CDC David J. Sencer Museum, Exhibitions, 2018. Available at [https://www.cdc.gov/museum/exhibitions\\_permanent.htm](https://www.cdc.gov/museum/exhibitions_permanent.htm).
24. L. Liburd, "Remarks at launch event for 'Health is a Human Right: Race and Place in America' at Georgia State University" (2017).
25. W. E. B. Dubois, *The Philadelphia Negro* (University of Pennsylvania Press, 1899).
26. W. E. B. Dubois, *The health and physique of the Negro American* (Atlanta University Press, 1906).
27. See N. Gaber, "Mobilizing Health Metrics for the Human Right to Water in Flint and Detroit, Michigan", *Health and Human Rights*, 2019, 21/1, pp 179-189.
28. See, e.g., J. Wolff, *The human right to health* (Norton, 2012).
29. See B. Salhi and P. Brown, "Teaching Health as a Human Right in the Undergraduate Context: Challenges and Opportunities", *Health and Human Rights*, 2019, 21/1, pp 191-202.

30. Willen (see note 11), p. 306.

31. P. Hunt, "Missed opportunities: Human rights and the Commission on Social Determinants of Health," *Global Health Promotion* 16/1\_suppl (2009), pp. 36-41; A. Chapman, "Missed opportunities: The human rights gap in the report of the Commission on Social Determinants of Health," *Journal of Human Rights* 10 (2011), pp. 132-150.



# Mobilizing Health Metrics for the Human Right to Water in Flint and Detroit, Michigan

NADIA GABER

## Abstract

The ongoing water crises in Detroit and Flint, Michigan, offer dramatic cases of retrogression in realizing the human right to water—particularly striking in a region that enjoys access to one-fifth of the world’s freshwater and a country that has historically enjoyed near-universal access to water and sanitation. Efforts to secure safe, sufficient, affordable, acceptable, and accessible water in these cities reveal a troubling inability to protect the human right to water through legal measures. Compounding the challenge is the lack of reliable government data on the scope and impacts of the water crises—a void that residents have organized to fill. Activists have engaged a number of citizen-led research projects to demonstrate the health impacts of unsafe and unaffordable water. This paper discusses the process and potential of such projects to advance the substance of the human right to water in the United States, considering their effects within and outside the law. These research efforts have significant methodological and legal constraints with respect to widespread water insecurity, exposing a serious vulnerability in communities’ ability to protect drinking water and public health in the United States through legal means. However, drawing on Amartya Sen’s theory of human rights, I elaborate the extra-judicial powers of human rights, emphasizing their power to galvanize action and articulate ethical demands. Citizen science is a powerful mode of engaging residents in the articulation—and quantification—of those human rights demands, as I demonstrate with local cases.

---

NADIA GABER, PhD, Department of Anthropology, History and Social Medicine, UCSE, San Francisco, CA, USA.

Please address correspondence to Nadia Gaber. Email: [nadiagaber@berkeley.edu](mailto:nadiagaber@berkeley.edu).

Competing interests: None declared.

Copyright © 2019 Gaber. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted noncommercial use, distribution, and reproduction in any medium, provided the original author and source are credited.



## Introduction

Water is a non-substitutable resource that is vital for biological, economic, and social life. As such, the human right to water and sanitation represents one of the most fundamental human rights claims in international law, though its interpretations and implementation strategies differ across the globe. In the United States, citizens enjoy near-universal connection to safe drinking water but have no legal right to receive water. The ongoing water crises in Detroit and Flint, Michigan offer dramatic cases of retrogression in realizing the human right to water, and reveal a troubling inability to secure safe, sufficient, affordable, acceptable, and accessible water through legal appeals. These retrogressions raise the need to examine the practices in place for ensuring water for all.

Michigan, like many states in the industrial American Midwest, has suffered serious economic devastation since the 1980s, with the decline of the automobile industry and the rise of globalization. Though the water crises in Flint and Detroit appear in different forms, they emerge from shared economic history and political decision-making. Just 70 miles apart, Detroit and Flint have become epicenters in the ongoing struggle for the human right to water in the United States, though unfortunately they represent wider challenges to water security. As of January 2019, more than 70 public drinking water systems in Michigan alone have higher levels of lead than Flint.<sup>1</sup> Moreover, experts estimate that the percentage of US households unable to afford water could top 35% by 2020—a threefold increase in five years.<sup>2</sup> The contamination of Flint's water system and the mass water shutoffs exercised in Detroit both represent violations of the human right to water, a framework that residents have embraced in their legal and organizing strategies.<sup>3</sup>

Residents of both cities have turned to community-led health research to demonstrate the severity of these violations and advocate for the fulfillment of the human right to water. I address how these health-based strategies might work to realize water security around and within the normative global framework of the human right to water

and existing US laws governing drinking water and public health.<sup>4</sup> I ask: Is there a role for health claims in advancing the international human right to water given a national legal context that does not recognize this right as such?

This question has reverberations for impacted communities across the country, and requires a layered consideration of how human rights claims, and the evidence used to support them, operate in and outside the law. Indeed, human rights, as Amartya Sen has consistently argued, are ethical as well as legal demands, and achieving them requires more than making new laws.<sup>5</sup> Realizing the human right to water demands the substantive fulfillment of the right and not just its recognition in name. Here, that may involve making new data.

This paper draws on ethnographic data gathered during eight months of fieldwork over two years in Detroit and Flint, Michigan, from March 2015 to February 2017. I describe how residents' use of community-based health research supports their human right to water. Citizen science offers supporting evidence of violations, concretizing the ethical stakes for community members and observers alike. It also empowers residents to hold the state accountable from the "bottom up"—not only to the letter of its own laws, but to the ethical standard that the human right to water demands.

Although the right to health and the right to water are highly interrelated in human rights law, health claims have limited purchase on securing safe and affordable water in the United States. I illustrate this as a function of methodological limitations, as well as legal and political constraints. By making the consequences of water denial salient in quantifiable terms, this research may support specific *retroactive* legal recourse, as many residents hope. I suggest that although this legal recourse does not prevent violations of the human right to water, pursuing damages through injury law may provide a financial deterrent to compel states to extend drinking water protections. I conclude by arguing that residents' use of health evidence and human rights claims exceeds this narrow legal space by encouraging recognition and action as Amartya Sen's writings suggest, drawing upon a

“social ethics” that exceeds the juridical instrumentality of the human right to water.

### The right to water in the United States: A principle without a prescription

It was not until 2010 that the United Nations (UN) established the human right to water and sanitation, despite the centrality of water to the realization of all human rights, and to sustaining life itself.<sup>6</sup> Previously, the human right to water was encompassed within two rights outlined by the International Bill of Human Rights: the right to life and the right to health. The right to life requires states to support “appropriate means of subsistence,” ensuring a bare minimum quantity and quality of water as necessary to survival. Under the right to health, defined as the obligation to promote and protect the “highest attainable standard of health,” the right to water could be interpreted more expansively, raising safety standards and including water for domestic and hygienic use.<sup>7</sup> This was further clarified in General Comment 15, a non-binding statement affirming the relationship of a right to water to existing economic, social, and cultural human rights, and outlining its dimensions: “The human right to water entitles everyone to sufficient, safe, acceptable, physically accessible and affordable water for personal and domestic uses.” These five normative criteria each have specific standards established by the UN and World Health Organization (WHO).

With the passage of resolution 64/292 in 2010, the UN established a binding framework that clarified the specific obligations of states and entitlements of all persons with respect to water and sanitation as an independent human right.<sup>8</sup> The framework also created an international mechanism of accountability for states that violate the human right to water. In practice, the ability of the UN Human Rights Council to compel states to comply with their human rights obligations varies widely. Delivering water and sanitation is an intensive infrastructural project, and many nations struggle to synchronize the political, economic, and social capital needed to respect, protect, and fulfill those obligations.<sup>9</sup>

The human rights framework allows for the “progressive realization” of the right to water, although some fear this may serve as a loophole that developing nations can use to evade making material gains in securing water for all.<sup>10</sup> The corollary to progressive realization is the principle of “non-retrogression,” which prohibits nations from moving backwards in their realization of the human right to water. Detroit’s mass disconnections offer one of the most striking examples of retrogression in the right to water. Caterina de Albuquerque, UN Special Rapporteur on the right to safe drinking water and sanitation, visited Detroit in 2014 and found the shutoffs to be in violation of the human right to water. She stated:

*I’ve been to rich countries like Japan and Slovenia where basically 99 percent of population have access to water, and I’ve been to poor countries where half the population doesn’t have access to water ... but this large-scale retrogression or backwards steps is new for me.*<sup>11</sup>

The United States abstained from voting on UN Resolution 64/292 and has not ratified the International Covenant on Economic Social and Cultural Rights (ICESCR), from which the human right to water and sanitation is derived, thus refusing to be legally bound by the terms of the human right to water.

Domestically, the United States does not recognize a right to water for its citizens or residents. No such right exists in the US Constitution, nor is it justiciable in the courts.<sup>12</sup> Though there are several local and federal civil rights statutes under which water terminations could be challenged, the standards of proof are very high, requiring that a demonstration of discriminatory intent or impacts rests on “a tight causal connection between *statistical proof* of racially disparate impacts and the government policies.”<sup>13</sup> Citing the situation in Detroit, legal scholar Sharmila Murthy has argued that the fundamental necessity of water to “life, liberty and the pursuit of happiness” justifies that access to water be considered what legal scholar Cass Sunstein calls a “constitutive commitment,” worthy of constitutional protections through legislation.<sup>14</sup> Only California has passed a law affirming

the human right to water, in 2012.<sup>15</sup> Two others, Massachusetts and Pennsylvania, mention the right to water in their state constitutions.<sup>16</sup> In Michigan, no such legal provisions exist, leaving drinking water rights in abeyance as state-appointed officials orchestrate fundamental changes to the provision of water and wastewater services.

Only one of the five aspects of the human right to water—safety—is protected under US law. The United States has two primary federal regulations in place to protect residents (and wildlife) from contaminated water—the 1972 Federal Water Pollution Control Act (amended in 1977 and renamed the Clean Water Act) and the 1974 Safe Drinking Water Act. The Clean Water Act is designed to limit pollution of the nation’s waters by regulating discharges, setting wastewater treatment standards, overseeing permits and licensing, and monitoring water quality compliance.<sup>17</sup> The Safe Drinking Water Act regulates drinking water quality for all public water systems in the United States, with the lead and copper rule issued pursuant to the SDWA in 1991.<sup>18</sup>

Notably, these laws protect water access through ‘negative’ rights—freedom *from* toxic exposure to harmful contaminants—but does not commit the United States or any state or local government to any ‘positive’ right *to* safe water. However, they remain the strongest legal protections for drinking water in the US, in large part because they are quantifiable and have justiciable legal avenues for redress. This enforcement is dependent on consistent regulation and good data—state responsibilities that were betrayed to disastrous effect in Michigan.

These legal architectures matter a great deal in the story of Detroit and Flint’s water crises, and they also go some way toward explaining why communities organized themselves to support their human rights-based claims with quantitative metrics. Residents have protested excessive pollution, rising rates, and other limitations on water access for years through electoral and legislative means to minimal effect. Instead, the appeal to human rights operates as a powerful “idiom of social justice mobilization,” to borrow anthropologist Sarah

Willen’s term, which places these crises strategically in global perspective.<sup>19</sup> By situating denials of safe and affordable water within international human rights, Michiganders seek to elevate the moral force of their appeal above the constraints of local politics or domestic law. They tie their struggles to a global paradigm that views water as a central imperative of economic development, gender equity, and health.

Amartya Sen has argued that, despite the strong synergy relating human rights to law, human rights are incompletely, if not mistakenly, understood as legal instruments. Human rights claims, he argues, “are best seen as articulations of social ethics” that produce effects through extra-legal routes as well as legal ones. For example, human rights may activate a “recognition route” that points out denials of fundamental human freedoms and galvanizes concerted organization to resist them.<sup>20</sup> In Michigan, the UN’s declaration of the Detroit shutoffs as a violation of human rights has galvanized a swell of organized responses, including community-based health research.

#### *From water security to water crisis*

In 2015, a WHO/UNICEF joint report estimated that 99% of US residents have access to safely managed drinking water and 89.5% have access to safely managed sanitation.<sup>21</sup> Yet threats to this water security are emerging across the United States, disproportionately affecting poor, minority, and rural communities. Many factors threaten US water security, including aging infrastructure, dwindling federal financing (from 78% of municipal sewer infrastructure in 1978 to just 5% today), increased private bottling of public groundwater, emerging contaminants from hydraulic fracturing, climate change-related water disasters, southern drought, and demographic changes, to name a few.<sup>22</sup>

The Detroit Water and Sewerage Department (DWSD) has been particularly imperiled since the city declared bankruptcy in 2013. The financial and political restructuring of DWSD—which serves 40% of Michigan’s population across 126 municipalities (nearly 4 million people)—has had serious

ripple effects on water security in the region. Rather than renew its contract with DWSD, the city of Flint, under a state-appointed emergency manager, began to source the city's water from the Flint River in 2014—but refused to budget for safe treatment. The result is the continued exposure of Flint residents to dangerous levels of lead and other harmful contaminants, as well as at least 12 deaths from one of the largest *Legionella* outbreaks in US history.<sup>23</sup> UN rapporteurs have rightly pointed out that there are potential violations here not only of the right to water, but also of the rights to housing, life, and the integrity of the family.<sup>24</sup>

In Detroit, meanwhile, DWSD aggressively escalated residential shutoffs for nonpayment in an effort to recoup nearly \$90 million in debt—without initially pursuing commercial accounts for back payments. In 2015 alone, 23,883 households—an estimated 64,000 people—lost water service in Detroit.<sup>25</sup> Though the disconnections were deemed a violation of the international human right to water by the UN and a public health crisis by National Nurses United, it has not been deemed a justiciable violation in the US legal context.<sup>26</sup> The practice continues today.

Globally, one of the major barriers to implementation of the human right to water has been the lack of reliable and effective monitoring data.<sup>27</sup> Having better data is correlated with better access to water.<sup>28</sup> Locally, data issues have ranged from overt manipulations of scientific evidence to withholding of records or failure to commission health impact assessments of these dramatic changes. This is particularly problematic in the US context where scientific certainty is used as a legal barrier to relief and redress, as opposed to the European Union's "precautionary principle" in which "scientific uncertainty" is a trigger for study and regulation on the part of nation-states.<sup>29</sup> In their human rights review, UN rapporteurs chided Detroit for this failing, noting that "the city has no data on how many people have been and are living without tap water, let alone information on age, disabilities, chronic illness, race or income level of the affected population."<sup>30</sup> In the following section, I focus on

those projects that sought to generate data in the absence of credible, public information about the water crises in spite of foreclosed legal protections of the right to water.

### Data from the ground up: Citizens study the water crises

Each of the five criteria of the human right to water was violated following the restructuring of water services in Detroit and Flint under emergency management, as residents repeatedly attest. Their anecdotal accounts structure local knowledge and practice about the water but are often met with official denials.<sup>31</sup> In this section, I recount some of the community-based research projects organized to quantitatively demonstrate the health impacts of these human rights violations. These "citizen science" projects are pursued alongside many modalities of protest and persuasion in the effort to achieve the human right to water, but I focus on the unique role of health research, as a scholar and activist engaged in this aspect of the work.

Use of community-based participatory research (CBPR) in Flint has by now widely demonstrated the power of quantification to validate the anecdotal claims of residents affected by poor water quality. In the early months of the water crisis, several open-source databases were created for residents to upload results of their blood tests or water lead levels. Partnership with academic researchers allowed these investigations to be conducted systematically and backed the findings with institutional credibility.<sup>32</sup> Two studies in particular garnered immense attention: a water quality study of Flint households initiated by Dr. Marc Edwards of Virginia Tech and Flint resident Lee Ann Walters, and a retrospective cohort study examining blood lead levels among Hurley Hospital pediatric patients by Dr. Mona Hannah-Attisha. Within weeks of the results emerging, a state of emergency was declared to address water rights violations that had been dismissed for more than two years.

Subsequent investigations in Flint have revealed that the Michigan Department of Environ-

mental Quality (MDEQ) was deliberately skewing the results of routine measurements in order to keep the city's water below the federal "action level" for lead.<sup>33</sup> These subtle, covert alterations enabled the state to ignore the health risks posed by Flint's drinking water for over two years, and raise serious questions about the reliability of data produced by those responsible for fulfilling the human right to water. At least 33 cities across 17 states have used the same water testing "cheats" to evade regulations.<sup>34</sup> Despite much attention, the water in Flint is still suspected to be unsafe, and no generalized protections have been implemented, aside from a slight lowering of the "action threshold" for lead at the state level.

Edwards has become one of many vocal critics of the politics of data production about water safety, arguing that the "top-down research model" is inherently dangerous to scientific integrity and public life when the funder—the government—is also responsible for the outcomes.<sup>35</sup> Instead, CBPR works outside of, or adjacent to, the state in order to produce data from the "bottom up," at some distance from the party responsible for water delivery. CBPR engages people as subjects, not just objects, of health studies and directs resources and attention to the priorities of community concern.<sup>36</sup> At its best, CBPR engages locals throughout the entire research process and includes an equitable distribution of credit and reward between institution- and community-based researchers. At its worst, CBPR siphons local expertise and energies, misrepresents community interests, or creates additional burdens. As media pressures have intensified, Edwards himself has become a charged figure in ongoing debates among scholars and practitioners about the complex power dynamics of citizen science.

With state science proving absent or suspect due to "top-down" political manipulation, nonetheless citizen science projects offer a powerful means of articulating the human right to water, showing the empirical stakes of the ethical demand. I now turn to Detroit, where I engaged in CBPR projects directed by a grassroots organization called We the People of Detroit.

In 2015, We the People of Detroit convened activists, professors, students, and volunteers into a Community Research Collective (CRC) to document the political and racial implications of the water shutoffs. The collective emerged as a response to the withdrawal of transparency and accountability on the part of the state, as Dr. Gloria House expresses: "Detroit community activists recognize that the water crisis and the other destabilizing policies...are leading to the erasure of our communities," she writes, "...but when we assert that reality, our perceptions are viewed by many as extremist. For that reason, we have sought data with which to measure our perceptions."<sup>37</sup> Recognizing the power of research to legitimate local claims, organizers have relied on citizen science to make their human rights claims visible: "[I]t's not about *if* our human rights are being violated," said one activist, "but about how much!"<sup>38</sup>

At a meeting with the Detroit Health Department, the director told our group that while the department did not have the money, nor the political clout, to investigate the health impacts of water shutoffs in the city, it would offer support if the community could "bring us the data."<sup>39</sup> The director made clear that "data" in this context meant quantitative, statistically significant findings based on a random sample—typically very expensive and time-consuming criteria.

To perform a city-wide survey of health needs in the wake of water shutoffs, our research collective adapted the methodology of a Centers for Disease Control and Prevention (CDC) toolkit called the Community Assessment for Public Health Emergency Response (CASPER).<sup>40</sup> Because the toolkit was designed for use in disaster settings, it outlines a rapid and inexpensive survey method that is nonetheless statistically representative and reliable. We assembled more than 40 volunteers over a 15-month period to canvass randomly selected city blocks. Our study documented several cases of health issues stemming from water disconnections, but we did not have the statistical power to extrapolate widely from these. We found what researchers worldwide know: that the nature of water insecurity



is multi-dimensional and, in many respects, resists quantification.<sup>41</sup> Moreover, the study was limited by the constraints of a random sampling method in a high-vacancy city, and the structure of cyclical, intermittent disconnections.<sup>42</sup>

Still, the research achieved important symbolic, social, and statistical objectives. Residents' adaptation of this toolkit symbolized the ethical stakes of what many consider a "man-made disaster," as well as their disbelief in public officials organizing a sufficient response to this public health emergency. The research project also became an organizing tool for social advocacy, as volunteers spread the word about the slate of advocacy efforts to support the human right to water. Statistically, although it could not sufficiently demonstrate causality, the research nonetheless established representative assessment of significant health vulnerabilities across the city. In doing so, it offered empirical support for recommendations advocating for the right to water as a matter of policy, not law. This includes the Wayne County Population Health Authority's call for a moratorium on water shutoffs for medically vulnerable groups, a call in accordance with international human rights principles of non-discrimination and protection of marginalized groups.<sup>43</sup> Based on our CASPER study, we estimated that 80% of Detroit households would be exempt from shutoffs if such a moratorium were implemented.<sup>44</sup> These striking findings were shared with the city council, the mayor's office, DWSD, and other state agencies, to no effect. One activist, a nurse herself, reported anecdotally that the mayor laughed off the findings, chuckling that if the vulnerable were exempted, there would be no one left to disconnect.<sup>45</sup>

In another study, the CRC partnered with the Global Health Institute at Henry Ford Hospital to conduct a geographic assessment of the impacts of shutoffs on water-related illnesses. With Henry Ford's internal patient data and a roster of DWSD shutoffs received through Freedom of Information Act (FOIA) disclosures, the team was able to show a significant, bidirectional relationship between water shutoffs and health impacts at a block by block

level. Between January 2015 and February 2016, patients who were diagnosed with a water-associated illness were 1.42 times more likely to have lived on a block that had experienced a water shutoff. Those who lived on blocks that experienced a shutoff were 1.55 times more likely to have been diagnosed with a water-related illness.<sup>46</sup> The results of the study were to be shared at a press conference that was abruptly cancelled, leaving some to speculate that the mayor's office may have pressured the hospital to downplay the findings, emphasizing that causation could not be proven.<sup>47</sup> We the People of Detroit nevertheless printed a summary flyer that was distributed to residents, discussed in "listening sessions" and shared at both academic and activist meetings. This data was later cited in journalism, philanthropy, and nonprofit reports on the water shutoffs, lending empirical validation and message amplification to residents' human rights claims. The institutional suppression of these findings also reflects on their power to tie the moral force of human rights claims to scientific evidence that can pressure governments to act, even if their current policies are legal.

### Metrics in court: Pursuing legal strategies for water security

Several lawsuits have been filed regarding the water crises in Flint and Detroit, providing some preliminary insight into the potential for using health impact data to legally secure water for all.

A major challenge for ensuring the right to water through health metrics is that only some of the normative principles are readily available to existing mechanisms of quantification and thus accountability—as our experience with the CASPER well demonstrates. This structure proves especially difficult where the human right to water is concerned because the impact of water insecurity is often better understood at the household or family level rather than the individual, rights-claiming person.<sup>48</sup> Moreover, the nature of the harms of water insecurity are often diffuse as they entail complex tradeoffs between health, money, digni-

ty, and time that may not manifest as measurable effects.<sup>49</sup> These methodological limitations inform the legal limitations of the role of health in securing the human right to water in Detroit and Flint.

The public health data generated from Detroit's community-based participatory research projects has not yet been tried in court, but an earlier ruling relating to the Detroit water shutoffs suggests that such data may not have legal purchase given that there are no constitutional rights protecting water. In 2014, residents filed an adversarial complaint during the then-ongoing bankruptcy proceedings, *Lyda et al. v. City of Detroit et al.*, seeking an injunction to halt the shutoffs, restore water service and compel DWSD to implement an affordability plan.<sup>50</sup> The city argued that official health department records failed to show that the water shutoffs were having a negative impact on public health. Arguably, there is a way in which the city of Detroit leveraged the absence of data in order to defend mass disconnections. The court, however, dismissed this argument, finding that "health department record compilations do not appear to be designed to measure the consequences of significant water service terminations in the City."<sup>51</sup> Yet even presuming irreparable harm to public health, the court held that "there is no constitutional or fundamental right either to affordable water service or to an affordable payment plan for account arrearages."<sup>52</sup>

By contrast, the suits underway regarding the Flint water crisis may find some traction because of the data quantifying the levels of toxicity in Flint's water and correlating this to measurable increases in blood lead levels. In January 2016, Flint residents filed two class action suits seeking damages resulting from the city's water contamination.<sup>53</sup> Among the legal charges levied is that the defendants violated substantive due process through an invasion of the fundamental right to bodily integrity. The scope of legal redress available to residents remains to be seen, but experts consider it unlikely that these tort cases will succeed, as the law requires a demonstration of "present, physical injury." Although the data is able to correlate the poor-quality water to lead exposure, it is difficult to definitively

tie this to injuries, as the physiological and psychological effects of lead emerge differently over the life course. This makes it difficult to substantiate in court, even though lead is known to be a potent, irreversible toxin.

The limitations of US law, the diffuse impacts of water insecurity, and the pressure to produce representative, scientific evidence of "present"—particularly with overt government failures to do so—constrain the ability to advocate for safe and affordable water in Michigan, and to realize the ideals of the human right to water. And yet this has not deterred local efforts to collect such data or demand their human rights. In so doing, they echo Sen's contention that human rights should not be bound by what is achievable under current conditions; instead, they express "the need to work towards changing the prevailing circumstances to make the unrealized rights realizable, and ultimately, realized."<sup>54</sup>

## Conclusion

In the United States, recent demographic, financial, and infrastructural challenges threaten the water security of residents in many cities, despite having previously met international standards. The contamination of Flint's water system and the mass water shutoffs exercised in Detroit represent dramatic violations of the human right to water precipitated by political and financial restructuring of water services. These are unprecedented retrogressions in the human right to water, and they may only be harbingers of more to come.

I have shown here that the United States' refusal to ratify the international human right to water, alongside the weak status of socioeconomic rights in the United States, constrains the legal route to securing the human right to water and sanitation for all. I have also shown that quantification studies may be limited methodologically in their ability to capture the complex scope of consequences stemming from violations of the human right to water. However, health evidence may still play a unique role in protecting the human right to water, most significantly by supporting ethical demands, poli-

cy recommendations, and local organizing efforts with robust, reliable data. The possibility of recovering from government malfeasance in drinking water provision is slim, though Flint residents' recourse to injury law may have an outside chance of deterring governments from taking such gross public health risks with respect to water provision. Despite this, health claims retain powerful political potential beyond the law when tied to human rights claims, which seek more than legal redress.

When asked about how to design research that can support a legal challenge to the city's water shutoffs, the CEO of We the People of Detroit was skeptical regarding the pursuit of legal protections: "Seems to me legal routes are the last resort because they usually take the longest and deal with the least," she cautioned. "What we're trying to do is build people power with statistical power... The goal is to inform, educate and empower the people who are most marginalized to live a full life."<sup>55</sup> The statement speaks to the ethical demand being made by residents not only to the human right to water as a matter of substance—achieving safe, sufficient, affordable, accessible, and acceptable water for all—but also as a matter of practice, enhancing the power and dignity of people in the process. CBPR, like human rights, works within and outside the law. Indeed, in this political and juridical environment, it may be more effective in the court of public opinion than in the court of law.

Human rights have demonstrated impact as more-than-legal tools. The amplification of human rights testimonies in media and film has helped foster a culture of respect for human rights the world over.<sup>56</sup> The slim literature specifically examining health litigation of human rights violations suggests that court decisions seldom set or interrupt state policy.<sup>57</sup> Rather, litigation inserts the language of rights into political discussions.<sup>58</sup> This literature suggests that even 'successful' litigation effects social change only when supported by protests, boycotts, and public campaigns.<sup>59</sup>

As ethical demands, human rights do not only affirm universal and already established values, Sen argues, but actively assert a claim to freedoms that can be achieved through coordinated action of

responsible actors. What is universal about these claims, then, is not (only) that they invoke shared values, but that they compel all who share responsibility in securing that value into action. To this effect, Sen also asserts that human rights claims should expect to survive "open and informed scrutiny" in the public sphere. With the ethnographic evidence presented here, I have suggested that community-based health research empowers human rights claims by helping them stand up to public scrutiny in a political environment that has otherwise erased the evidentiary basis of continued denials of safe and affordable water in Michigan. While acknowledging the methodological and legal limitations of employing health metrics to secure water in the United States, I hope at the same time to have shown here that the power and possibility of community-based research in advancing the human right to water is not only real but also vital.

## References

1. R. Fonger, "71 Michigan water systems now have higher lead levels than Flint," *MLive* (October 30, 2017). Available at [https://www.mlive.com/news/flint/2017/10/71\\_michigan\\_water\\_systems\\_had.html](https://www.mlive.com/news/flint/2017/10/71_michigan_water_systems_had.html).
2. EA. Mack, S. Wrase, "A burgeoning crisis? A nationwide assessment of the geography of water affordability in the United States," *PloS one* 12/1 (2017): e0169488.
3. S. Howell, M. Doan, A. Harbin, "Detroit to Flint and back again: Solidarity forever," *Critical Sociology* 45/1 (2019), pp. 63-83.
4. See M. Barlow, "Our right to water: a people's guide to implementing the United Nations' recognition of the right to water and sanitation," The Council of Canadians (2011). Available at <http://www.right2water.eu/sites/water/files/righttowater-0611.pdf>.
5. A. Sen, "Elements of a theory of human rights," *Philosophy and Public Affairs* 32/4 (2004), pp. 315-356.
6. UN Committee on Economic, Social and Cultural Rights, General Comment No.15 20/01/03 (29th session, Nov. 2002) The Right to Water (Arts 11 and 12 of the Covenant), E/C.12/2002/11 (hereafter referred to as GC15), Adopted Tuesday 26 Nov. 2002.
7. E. Bluemel, "The implications of formulating a human right to water," *Ecology LQ* 31 (2004), pp. 957-1005.
8. G.A. Res. 64/292, U.N. Doc. A/RES/64/292 (August 3, 2010); G.A. Res 64/PV.108, U.N. Doc. A/RES/64/PV.108 (July 28, 2010); Press Release, General Assembly, General Assembly Adopts Resolution Recognizing Access to Clean

Water, Sanitation as Human Right, By Recorded Vote of 122 in Favour, None Against, 41 Abstentions, U.N. Press Release GA/10967 (28 July 2010).

9. C. De Albuquerque, "Realizing the Human Right to Water and Sanitation: A Handbook by the UN Special Rapporteur," United Nations (2014).

10. C. Acey, "Hybrid governance and the human right to water," *Berkeley Planning Journal* 28/1 (2016), pp. 10-39.

11. L. Gottsendier, "UN officials 'shocked' by Detroit's mass water shutoffs," *Al Jazeera America* (October 20, 2014). Available at <http://america.aljazeera.com/articles/2014/10/20/detroit-water-un.html>.

12. E. Thor, "The human right to water in the United States: Why so dangerous?" *Global Business and Development Law Journal*, 26 (2013), pp. 315-341.

13. M. Davis, "Let justice roll down: a case study of the legal infrastructure for water equality and affordability," *Georgetown Journal on Poverty Law and Policy*, XXIII/3 (2016), pp. 355-393.

14. S. Murthy, "A new constitutive commitment to water," *Boston College Journal of Law & Social Justice* 36/159 (2016), pp. 159-233.

15. AB 685, ch. 524, 2012 Cal. Stat. 91 (Codified at Cal. Water Code § 1063).

16. See Constitution of the Commonwealth of Massachusetts, art. XCVII. And Constitution of the Pennsylvania, Art. 1, sec. 27.

17. U.S.C. § 1251 *et seq.*

18. U.S.C. § 300f.

19. S. Willen, "Do 'illegal' im/migrants have a right to health? Engaging ethical theory as social practice at a Tel Aviv open clinic," *Medical Anthropology Quarterly* 25/3, pp. 303-330.

20. A. Sen, "Human rights and the limits of law," *Cardozo Law Review* 27 (2005), pp. 2913-2927.

21. World Health Organization and UNICEF. 2015. "Progress on drinking water, sanitation and hygiene: 2015 update and MGD assessment," *WHO Press* (Geneva).

22. Food and Water Watch, "The State of Public Water in the United States," Food and Water Watch (Washington DC, 2016), pp. 1-20.

23. D. O. Schwake, E. Garner, O. Strom, et al. "Legionella DNA markers in tap water coincident with a spike in Legionnaires' disease in Flint, MI," *Environmental Science and Technology Letters* 3/9 (2016), pp. 311-315.

24. United Nations Office of the High Commissioner for Human Rights. 2016. "Flint: 'Not just about water, but human rights' – UN experts remind ahead of President Obama's visit (GENEVA, 3 May 2016)." Available at <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=19917&LangID=E>.

25. K. Fried, "As Flint Residents Drank Poisoned Water, 20,000+ Detroit Households Lost Water Service Last Year," Food and Water Watch (2016). Available at <https://www>.

[foodandwaterwatch.org/news/flint-residents-drank-poisoned-water-20000-detroit-households-lost-water-service-last-year](http://foodandwaterwatch.org/news/flint-residents-drank-poisoned-water-20000-detroit-households-lost-water-service-last-year).

26. National Nurses United, "Nurses, activists cite public health emergency in Detroit water shutoffs," *National Nurses United* (July 17, 2014). Available at <http://www.nationalnursesunited.org/press/entry/nurses-activists-cite-public-health-emergency-in-detroit-water-shutoffs/>.

27. M. Langford and I. Winkler, "Quantifying water and sanitation in development cooperation: power or perversity?" Social Science Research Network (June 6, 2013). <http://papers.ssrn.com/abstract=2278656>.

28. Ibid.

29. T. Aven, "On different types of uncertainties in the context of the precautionary principle," *Risk Anal.* 31(2011), pp. 1515-1525.

30. UNHCR (see note 24).

31. H. L. Spiertz, "Water rights and legal pluralism: some basics of an anthropological approach," (presentation at Crossing Boundaries, the Seventh Biennial Conference of the International Association for the Study of Common Property, Vancouver, BC, Canada, June 10-14, 1998). Available at <https://dlc.dlib.indiana.edu/dlc/handle/10535/1298>.

32. A. Krings, D. Kornberg, and E. Lane, "Organizing under austerity: how residents' concerns became the Flint water crisis," *Critical Sociology* 00/0 (2018).

33. A.M. Barry-Jester, "What went wrong in Flint?" *Five Thirty Eight* (January 26, 2016). Available at <https://fivethirtyeight.com/features/what-went-wrong-in-flint-water-crisis-michigan/>.

34. O. Milman and J. Glens, "At least 33 US cities used water testing 'cheats' over lead concerns," *The Guardian* (June 2, 2016). Available at <https://www.theguardian.com/environment/2016/jun/02/lead-water-testing-cheats-chicago-boston-philadelphia>.

35. M. Edwards and A. Pruden, "The Flint water crisis: overturning the research paradigm to advance science and defend public welfare," *Environmental Science and Technology* 50 (2016), pp. 8935-8936.

36. N. Wallerstein and B. Duran, "The theoretical, historical and practice roots of CBPR," in M. Minkler and N. Wallerstein, eds, *Community-Based Participatory Research for Health: From Process to Outcomes* (San Francisco: John Wiley & Sons, 2008), pp. 25-46.

37. We the People of Detroit Community Research Collective, *Mapping the Water Crisis: The Dismantling of African-American Neighborhoods in Detroit* (2016) Detroit, MI: Creative Commons.

38. Author's fieldnotes, June 2016.

39. Author's fieldnotes, July 2015.

40. Centers for Disease Control and Prevention (CDC), Community Assessment for Public Health Emergency Response (CASPER) Toolkit: Second edition. Atlanta (GA):

CDC; 2012.

41. E. Stevenson et al, "Water insecurity in 3 dimensions: An anthropological perspective on water and women's psychosocial distress in Ethiopia," *Social Science and Medicine* 75 (2012), pp. 392-400.

42. We the People of Detroit, forthcoming.

43. E Cantu, "Access to Water Service in Detroit Continues to be a Population Health Issue," *Authority Health* (August 23, 2016).

44. We the People of Detroit, forthcoming.

45. Author's fieldnotes.

46. A. Plum, K. Moxley, B. Zervos, "The impact of geographical water shutoffs on the diagnosis of potentially water-associated illness, with the role of social vulnerability examined," in press.

47. M. Kovac, "Did the Detroit Mayor's office suppress damaging water shutoffs study?," *Truthout* (July 15, 2017).

48. K. Bakker, "Commons vs commodities: debating the human right to water," in F. Sultana and A. Loftus, eds. *The Right to Water: Politics, Governance and Social Struggles* (Abingdon: Earthscan, 2012).

49. I Ray, "Women, water and development," *Annual Review of Environmental Resources* 32 (2007), pp. 421-449.

50. *Lyda et al. v. City of Detroit* at 5-6, No. 13-53846 (Bankr. E.D. Mich. Sept. 29, 2014).

51. *Ibid.*

52. *Lyda et al. v City of Detroit* (see note 65).

53. *Melissa Mays, et al. v. Gov. Rick Snyder, et al.*, No. N/A, Mich. Clms., and *Melissa Mays, et al. v. City of Flint, et al.*, No. 16-N/A. Mich. Cir., Genesee Co.

54. A. Sen, "Human rights and the limits of law," *Cardozo Law Review* 27 (2005): 2913-2927.

55. Author's fieldnotes.

56. M. McLagan, "Human rights, testimony and transnational publicity," in M. Feher, ed. *Governmental Politics* (New York: Zone Books, 2007).

57. S. Gloppen and M.J. Roseman, "Can litigation bring justice to health?" In A.E. Yamin and S. Gloppen, eds *Litigating Health Rights: Can Courts Bring More Justice to Health?* (Cambridge: Harvard University Press, 2011).

58. V. Gauri & D.M. Brinks, "Introduction: the elements of legalization and the triangular shape of social and economic rights." In *Courting social justice: Judicial enforcement of social and economic rights in the developing world* (Cambridge: Cambridge University Press, 2008).

59. C. Coleman & L. Rubinowitz, "Social movements and social-change litigation: synergy in the Montgomery bus protest," *Law and Social Inquiry* 30/4 (2005), pp. 663-737.





# Teaching Health as a Human Right in the Undergraduate Context: Challenges and Opportunities

BISAN A. SALHI AND PETER J. BROWN

## Abstract

This paper explores the possibility of a pedagogy about health and human rights that is understandable and persuasive to undergraduate students yet does not succumb to a reductive dualism of optimism and pessimism. In 2014, we presented the topic of health and human rights in an introductory undergraduate global health course in conjunction with the exhibit “Health is a Human Right: Race and Place in America” at the Centers for Disease Control in Atlanta, Georgia. The exhibition highlighted the United States’ complicated legacy and failures of health and human rights, with an emphasis on ongoing racial and socioeconomic inequities. In conjunction with class lectures, students viewed the exhibit and submitted a survey and a reflective essay about human rights abuses, as well as possibilities for realizing the right to health in the United States. Contrary to our expectations, the human rights issues surrounding the AIDS epidemic raised very little interest among our students, for whom AIDS is a preventable and treatable chronic disease. Instead, students were most interested in exhibits on eugenics and forced sterilization, deficits in water and sanitation, racism, and contradictions of American exceptionalism. We conclude that an emphasis on the violations of human rights and their health effects using domestic examples from relatively recent history can be an effective pedagogical strategy. This approach represents an opportunity to counter students’ presumptions that the United States exists outside of the human rights discourse. Moreover, this approach may reinforce the idea that the domestic race- and class-based inequalities can and should be understood as human rights violations.

---

BISAN A. SALHI, MD, PhD, is an assistant professor in the Department of Emergency Medicine, Emory University School of Medicine, and affiliated faculty in the Department of Anthropology, Emory College of Arts and Sciences, Atlanta, GA, USA.

PETER J. BROWN, PhD, is a professor of anthropology, Emory College of Arts and Sciences, and Professor of Global Health, Department of Global Health, Rollins School of Public Health, Emory University, Atlanta, GA, USA.

Please address correspondence to Bisan Salhi. Email: [bsalhi@emory.edu](mailto:bsalhi@emory.edu).

Competing interests: None declared.

Copyright © 2019 Salhi and Brown. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted noncommercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

## Introduction

The idea of health as a human right was codified in Article 25 of the 1948 Universal Declaration of Human Rights (UDHR) and reiterated in many subsequent treaties and declarations. The “human right to health” is now a well-established platform within global health policy, action, and research.<sup>1</sup> While this right has galvanized successful health activist movements across the world, it has not gained as much popular traction in the United States. Political discussion of the right to health is often conflated with access to and financing of “health care,” so that the discourse focuses on promoting “cost-effective” and “value-driven” health services and products.<sup>2</sup> At the same time, discussion of human rights violations and their health consequences often harkens images of starving children or political conflicts in distant parts of the world. Dispelling the myth that human rights violations happen “over there” often proves difficult. The undergraduate classroom is an important place to sustain engagement with students about the human right to health and to unsettle assumptions about these violations. In 2014, we taught an introductory undergraduate global health course to 168 undergraduate students, most of whom were in their first or second year of enrollment. Our course was required for the global health minor but was also open to all undergraduates at Emory University.

Many undergraduates in the United States are drawn to human rights-based activism in an idealistic fervor to help alleviate extreme poverty and suffering in the Global South. Students sincerely want to help “save the world.” This passion, however, often stands in tension with unfamiliarity, misunderstanding, and skepticism. Global health courses are an ideal place to explore these tensions and to temper idealistic fervor with humility and a realistic understanding of the complexities of health inequalities.<sup>3</sup> This requires formal cultivation and grounding in both historical and contemporary evidence. Indeed, few undergraduates have more than a cursory understanding of health and human rights, and fewer still have more than an abstract notion of what the violation of such rights entails. Few fully appreciate the fundamental premise of

international human rights treaties, namely the claim that basic human rights are owed to every human being, regardless of the sociopolitical context into which an individual may be born.<sup>4</sup> These rights include both protection from harm as well as access to material goods necessary for a meaningful life. The rights are both aspirational and legally codified in international law—but they are violated with regularity and impunity in the United States.

Despite many students’ dedication to social justice and health equity, there is a tendency to normalize health inequities and violations of human rights that are happening in neighborhoods, cities, and reservations across the United States. Students tend to attribute these injustices to “just the way things are” or to justify poverty in the United States as a condition that is “not as bad” as that in the Global South. Such misconceptions are pervasive in the United States and, as has been demonstrated in other contexts, students throughout the world are themselves entangled within political and historical contexts that shape their preconceptions and their own emotional responses to pervasive human rights violations around them.<sup>5</sup> This disconnect is especially pronounced for undergraduate college students, particularly those enrolled at elite universities, most of whom never lacked or even worried about access to basic necessities and whose health and well-being has been invisibly subsidized by social and institutional networks. Even as racial injustice and economic inequality have gained long-overdue attention in American popular media, these have rarely been linked to the human right to health. Further, even when students are made aware of these pervasive and ongoing violations, it is difficult to break their ideological barriers and engage them in transformative possibilities.<sup>6</sup> To address these difficulties, scholars have called for pedagogical approaches that critically examine human rights violations in nations with ostensibly strong commitments to human rights, with the goal of linking these pedagogical approaches to ongoing struggles for social justice.<sup>7</sup>

In this paper, we apply this approach to a US context and present our experiences teaching undergraduate students about the inextricability

of racism, poverty, inequality, and health using the Center for Disease Control and Prevention's (CDC) Smithsonian-affiliated Sencer Museum exhibition "Health is a Human Right: Race and Place in America." A version of the exhibition is available online via Georgia State University: <https://exhibits.library.gsu.edu/exhibits/show/health-is-a-human-right>. The exhibition was designed to commemorate the 25<sup>th</sup> anniversary of the Office of Minority Health and Health Equity (OMHHE) at CDC.<sup>8</sup> It ran from September 28, 2013 to April 25, 2014, drawing a record of nearly 50,000 visitors, and used video and still images, as well as historical artifacts and digital renderings of epidemiological findings, to show how institutionalized racism, colonialist logic, and structural violence have shaped American health policy and interventions, harmed the health of Americans, and contributed to the egregious health inequities that persist in the United States today. The exhibition was a powerful new way to engage our students with history, and to convey what we otherwise could not—namely the immeasurable and ongoing suffering brought on by human rights abuses, as well of the historical evidence that activism organized around a human rights framework had made a difference.<sup>9</sup> The exhibition covered a range of historical episodes and themes, thereby challenging current biomedical conceptualizations that consider "health" solely within the individual body. It included images of injustices such as the forced relocation of Native Americans, the involuntary sterilization of Chicana women, and the internment of Japanese-Americans. It also challenged simplistic narratives of exploitation by highlighting signature moments of collective resistance, mobilization, and activist fervor: the 1968 Memphis Sanitation Strike and the Poor People's March in the same year; the Safeway agricultural boycott of the 1970s; and the 1991 ACT UP campaign to pressure Dr. James Curran, then-head of the CDC's HIV/AIDS Task Force, to expand the AIDS case definition by sending him 20,000 postcards showing his own face marked with a red and white bull's eye.

This visual imagery provided us, as teachers, with a way to engage our students in the concrete,

meaningful, and human experiences in the struggle for health and human rights in the United States. It was also an important way to transcend the limits of traditional methods (such as lectures, statistics, graphs, and international declarations by United Nations agencies) and draw our students' attention to the realities of both historical and ongoing struggles for human rights throughout the world, but especially in the United States.<sup>10</sup> By incorporating the CDC exhibition into our syllabus, we hoped to develop our students' interest in pressing contemporary inequalities, while empowering them to believe that their future actions can contribute to the struggle for human rights in the United States.

Our students' responses to the information and imagery presented in the exhibition was revelatory. We were surprised to learn that material which had resonated with all of us as teachers seemed outdated or irrelevant to our students. Conversely, our students found case studies from the exhibit compelling that we would not have considered incorporating into our classroom. Reflecting on this experience, this paper illuminates how the right to health is interpreted across generations. In what follows, we discuss the challenges we faced teaching health as a human right to undergraduates. We then describe our experience with assigning the CDC exhibition and incorporating its contents into the classroom. Next, we present results from a thematic analysis of our students' responses that revealed the four themes that resonated most with the students. Finally, we consider the challenges and opportunities in using this approach to teach health and human rights.

## Background

Like many American colleges, Emory University has embraced global health as part of its liberal arts curriculum, and now offers an undergraduate minor concentration in global health.<sup>11</sup> Our class served as an introduction to global health within this curriculum, spanning issues such as principles of population health, social and physical determinants of health, the history of global health, and contemporary global health interventions.<sup>12</sup> We

sought to incorporate health and human rights in a way that neither advanced a two-dimensional triumphalist narrative, nor focused exclusively on violations, thereby casting doubt on the transformative potential of human rights-based activism. Our approach to health and human rights was incorporated into a traditional lecture-based format.

We began with definitions of human rights, and provided a historical background on the United Nations' (UN) 1948 Universal Declaration of Human Rights (UDHR), which in Article 25 lists health along with 30 other human rights.<sup>13</sup> We also introduced the World Health Organization (WHO) constitution and the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 12.<sup>14</sup> Drawing on WHO's holistic definition of health, we elaborated on the synergy between health and human rights by stressing the indivisibility of human rights; that is, their inextricability from political, economic, and social rights.<sup>15</sup> As anthropologists, we incorporated into our teaching the critique that human rights are imbued with moral claims derived from principles of liberal law.<sup>16</sup>

Rather than focusing exclusively on violations, which we feared could make our students disengaged and/or cynical, we took a positive approach to teaching health and human rights. We provided a detailed description of the notable successes of the health and human rights movement. Specifically, we focused on the accomplishments of Jonathan Mann and his work in HIV/AIDS activism, and the legal struggles to provide access to antiretroviral therapy in South Africa.<sup>17</sup> The positive teaching strategy complemented topics that had been previously discussed, such as structural violence, the complexity of global health problems, and severe health inequalities.

Although our students were highly engaged in most of the course material throughout the semester, they seemed simply disinterested in the topic of health as a human right. They were unexcited by the examples presented and seemed disconnected from the transformative potential we sought to relate to them. The lectures fell flat. We theorized that their disinterest was, in part, because the legalistic emphasis of human rights lent itself to the

confusion of human rights and civil rights—an issue that dates back to the post-Second World War era, when American politicians maintained that atrocities within the United States should be exempt from external scrutiny.<sup>18</sup> Our students, for example, regularly conflated violations of human rights with violations of legal or constitutional rights. This may have been exacerbated by the fact that the United States has no formal commitment to a right to health for all citizens. Students thought that this topic was aspirational, and perhaps naïve; they had difficulty imagining successes built around the claims of the human right to health. Similarly, it was difficult to decenter the peculiarly American political struggle with health insurance and the Affordable Care Act (ACA), which was a major national issue at the time we integrated the CDC exhibition into our teaching. The prominence of the ACA in contemporary discourse reinforced our students' conflation of health with access to medical technologies; this detracted from the larger points we were attempting to convey and made health as a human right not about social justice and social welfare.<sup>19</sup>

When we had the unique opportunity to coordinate the course with the CDC exhibit, we were optimistic. In the current age of social media, the exhibition had the potential to immerse our students in a way that traditional lectures could not. Furthermore, we hoped that the exhibit's exclusive focus on the United States would both challenge the conflation of health and health care and reiterate the import of structural violence to ongoing human rights abuses in the United States.

## Methods

Emory University is physically adjacent to the CDC, and the exhibition was free to the public, so our 168 students were able to take a self-guided tour. In addition to submitting notes from the field trip, we asked them to write a series of short essays to reflect on the legacy of the human rights abuses addressed in the exhibition and to generate ideas for realizing the right to health in the United States. For the purposes of this paper, we focus on students' responses



to the following prompt: “Which exhibition [display] did you find most surprising and why? Don’t say you ‘never knew about this,’ instead perhaps reflect on why this is not widely known.”

We analyzed our students’ responses thematically. Our methodological approach consisted of the following procedure: 1) familiarizing ourselves with the data; 2) generating initial codes; 3) searching for themes; 4) reviewing the themes; 5) defining and naming the themes.<sup>20</sup> Both authors reviewed all student responses multiple times and independently identified key themes. When there was a disagreement about the themes or the interpretation of the content of the data, the authors discussed and resolved it. This method is appropriate for the qualitative description we offer below. Our analysis revealed four major themes from our students’ responses: 1) eugenics and forced sterilization; 2) racism and health disparities; 3) poverty—living without the basics; and 4) grappling with American exceptionalism.

We recognize that our students’ responses were generated in the context of a graded assignment, which may have led them to exaggerate or tailor their responses in anticipation of our expectations. Nevertheless, the exhibition provided a wide-ranging overview of human rights violations in the United States, and we believe that the themes with which students chose to engage provide important insight into their perspective. For example, the exhibits on HIV/AIDS—a topic that inspired much of the health and human rights movement—did not pique students’ interest; less than 1% of students chose to engage with this topic.

We elaborate on the themes generated from our students’ responses to the exhibition in the following section.

### Theme 1: Eugenics and forced sterilization

The most popular theme expressed in our students’ responses was shock at the compulsory sterilization programs that were practiced throughout the United States. Nearly a third (31%) of the class wrote about this topic. The Supreme court upheld the legality of forced sterilization in 1927, with 32 states

allowing the practice in 1937. Although this practice began to decline in the 1960s, in some areas it continued through the 1980s and the laws remained on the books until the 21<sup>st</sup> century. In these programs, women of predominately ethnic minorities, as well as women with “mental defects” were sterilized against their will or without their knowledge in many states.<sup>21</sup> The coercion sometimes came in the form of threats to their welfare benefits, but often it was without their knowledge and while they were in the hospital for unrelated reasons. At the same time, the eugenics movement, which advocated controlled reproduction to increase the occurrence of desirable heritable characteristics and “improve” the human population, gained widespread acceptance in the United States.<sup>22</sup> Some students expressed outright disbelief and indignation after seeing this portion of the exhibit. “I couldn’t believe that there was actually a eugenics movement in the United States, and actual laws passed that supported sterilization,” one student said. Another echoed this sentiment: “The practice of forced sterilization goes against every value and moral that the United States claims to represent.” Many students did not realize that eugenic policies were widespread in the United States. Others appealed to a human rights narrative in expressing their opposition to this practice. “Being able to give birth is a right that all women should have,” proclaimed one student. Yet another proclaimed the practice “unconstitutional.” And while the US Constitution does not guarantee all citizens the right to give birth, the UDHR does contain provisions related to the right to family and family planning (Article 12b). Our students therefore displayed an intuitive sense of—and support for—certain human rights without the vocabulary or framework to anchor these sentiments. Yet they were unaware that human rights are dynamic legal tools and principles that apply in regional, national, and international spheres.

The eugenics movement was in severe violation of UDHR principles. The Committee on Economic, Social and Cultural Rights and the Committee on the Elimination of Discrimination against Women (CEDAW) have both declared that women’s right

to health includes their sexual and reproductive health.<sup>23</sup> However, there is room for disagreement in how governments should realize the rights to family and family planning. Empowering women to take control over their reproductive health is much more divisive and contentious than recognizing that women have been robbed of these rights in these egregious violations. These complexities highlight a broader difficulty with teaching health and human rights: the fact that human rights are easiest to recognize in their negation. Thus, mobilizing social protests against violations is easier and more feasible than mobilizing activism for change.<sup>24</sup> A human rights frame can help explain situations of grave health inequities and injustices, but this does not make human rights the preferred “idiom of social justice mobilization.”<sup>25</sup> Ultimately, the absence of a human rights approach from key US struggles leaves students confused, and perhaps unconvinced, about its value.

## Theme 2: Racism and health disparities

A similar problem exists in linking racism and health disparities. Structural violence, racism, and social inequalities in health had been significant topics in earlier sections of our course and were not new to our students. Therefore, it was a surprise to us that another large portion of students (27%) seemed astonished to connect the effects of structural racism to health disparities in the United States. Perhaps the museum’s tangible exhibits documenting the links between racial discrimination and health forced them to confront these travesties while they seemed vague and distant before. One student commented:

*I found the exhibit about structural racism the most surprising. I have always thought about racism as a distant idea that is very political. I have never really thought about how racism can bleed into every aspect of life and influence health. The exhibit talks about how private institutions like banks, schools, and transportation systems can have such an impact on the health of minority populations. When groups of people are not given the same access to transportation, education, and financing, it can*

*take a toll on their health and the opportunities they have for improving health and living conditions.*

Another student was drawn to a video entitled *Excerpts from All My Babies: A Midwife’s Own Story*, about an African-American “granny” midwife from rural Georgia in 1953. The student wrote:

*The video compelled [sic] me because it showed in vivid detail the disparity in living conditions among Americans in different socioeconomic standings. In a scene in which a poor African-American woman was in labor, I could see flies flying and sitting on the mother. No one attempted to swat the flies because everyone seemed to be accustomed to the unsanitary living conditions. If the video was muted and shown today, people may think it was filmed in poor countries, such as certain African countries.*

Others pointed to the sordid history of medical experimentation, using examples from the Tuskegee syphilis study and the use of Henrietta Lacks’ cells in ongoing medical and pharmaceutical research. In the Tuskegee Study, researchers sought to observe the natural history untreated syphilis in African-American men, which involved withholding treatment even after the advent of penicillin. Henrietta Lacks was an African-American cancer patient at Johns Hopkins University and the unwitting donor of the HeLa cell line, one of the most important and widely used cell lines in medical research. One student noted, “In fact, I use HeLa-derived cells in my HIV research in the Emory Vaccine Center. However, Lacks’ family has not benefited financially from her legacy and did not know for decades that her cells were being used.”

The ways in which these individual cases reflect broader processes of racism and inequality are commonly discussed in medical anthropology, social medicine, and human rights, having been articulated over a century ago by Rudolf Virchow and W.E.B. Dubois, among others.<sup>26</sup> Yet these ideas remain foreign to many undergraduate students, many of whom are accustomed thinking about health as the sum total of genetics and personal choice, and the practice of medicine as a purely technocratic endeavor. As a result, they conceptu-

alize health as a depoliticized matter, divorced from issues such as racism and structural violence.<sup>27</sup> When health is linked to a range of pervasive human indignities, students are intimidated and confused by such “big questions.” This confusion is compounded when these pervasive social inequities are juxtaposed with the questions: Should there be a minimum guaranteed right to health? What basic minimum would the right to health require? The realization of rights necessarily involves conflict, the clash of interests, and divergent ideals.<sup>28</sup> Often, human rights claims signify the beginning, rather than the resolution of these conflicts. Of course, attention to these specificities may lead to short-term gains, but may ultimately divert from full realization of political and economic rights that is a prerequisite for health. Put another way, the difficulty is this: is it possible to take immediate steps towards public health goals without reinforcing and legitimating preexistent inequality, discrimination and inequality? This question is born of students’ frustration and struggle to understand and apply human rights principles to the world around them.

### Theme 3: Living without the basics of water and sanitation

As an answer to this conundrum, many of our students (20%) referenced the 639,000 American households without indoor plumbing, shown in the section of the exhibition entitled “Living Without the Basics.” One student wrote:

*[This exhibit] showed a corroded pipe and stated that in 2011, safe drinking water and sanitary sewage disposal is still unavailable for 13% of American Indian and Alaskan native homes on reservations, compared to 1% of the total population. This shocked me because as a developed country, I expected all citizens to have access to water and sanitation.*

Another remarked, “It’s hard to believe that water-borne diseases still exist in some communities in the US... These people are mostly the poorest in the country, living in rural and urban communities.” This assignment predated the public outcry over

the Flint water crisis, but our students were pondering these issues at precisely the same time that Flint switched its water supply to the Flint River, prompting residents to complain about the water’s color, taste, and odor, and to report rashes and concerns about heavy metal toxicity and bacterial contamination.

Students also invoked the trope of the “developed” vs. the “developing” nation in expressing their surprise about inequalities in access to essentials like clean water. One student observed,

*The work on delivering safe and clean water is focused on developing countries. However, I failed to realize that many households in America also lack indoor plumbing and access to sanitation services. The corroded water pipe with the bottle of filthy water made an impression on me because I would not have imagined that it was the water used by someone in the United States.*

Another student stated, “Poverty in a wealthy country often goes unnoticed, and the consequences of poverty go beyond simply lacking basic necessities.” The exhibit included information on water and health in several US regions, including the Central Valley of California, where residents struggle to access clean drinking water; Warren County, North Carolina, where toxic chemicals from a nearby factory polluted the water and soil; and “Cancer Alley,” an 85-mile stretch of actively polluting factories between Baton Rouge and New Orleans, Louisiana. Throughout the United States, growing racial and socioeconomic divisions are reinforced and reproduced in the differential enforcement of civil and economic rights, and manifested in stark health disparities.<sup>29</sup> These processes are neither new nor isolated in our history. Our Global Health course had already considered water and health issues in low- and middle-income countries, but the exhibition demonstrated that global health also refers to health inequalities at home.

Some students focused on the successes and potential of human rights activism. Some, for example, expressed hope that successful litigation would either stop hazardous waste dumping or move polluting factories away from residential communities.

Others cited the Bucket Brigade Program, in which citizens organized themselves and received funding from the Environmental Protection Agency (EPA) to build low-cost, innovative monitors to measure and publicize toxic release from a nearby refinery and provide data for later lawsuits.

This example highlights the community achievements and transformative potential of health and human rights activism. It highlights the inextricability of local and national politics. More importantly, this case illustrates how the CDC exhibition used visual imagery to illustrate important “wins” and “losses” in the struggle for human rights. These cases may seem mundane and small if described in other contexts (e.g., a lecture or in an assigned reading), but the images employed in the exhibit showed how these so-called small battles can have profound and lasting effects across generations. This was a pedagogical lesson we had hoped to instill in our students.

#### Theme 4: Grappling with American exceptionalism

Although some students readily accepted the role of human rights violations within American history, many others (20%) expressed some discomfort and difficulty reconciling the tangible evidence of human rights violations with their ideological beliefs and assumptions of “American ideals.” As they struggled to come to terms with the consequences of the eugenics movement, growing inequalities, and widespread poverty, our students expressed their surprise that these human rights violations were both recent and ongoing. Several, for example, were shocked that the final remaining eugenics law was repealed in 2008 in Mississippi. Again, viewing the exhibition over a year before the publicization of the Flint water crisis, others had dismissed the struggle for clean air or water as struggles of previous generations, or battles that had already been fought and won on behalf of the American people.<sup>30</sup> One student wrote, for example, that the United States is a country that “prides itself on equality, civility and protection of its people and their rights.” Surely, such violations could only happen in China or Nazi

Germany, others remarked. Many of our students mused that such atrocities are not publicized due to the embarrassment or shame of those involved. We were pleased that a few students explicitly noted that discrimination and inequality are embedded in the fabric of American history and society, and that this reality has palpable effects on human suffering and health. One student observed:

*The exhibition has one central message; [sic] American history has been fully of inequality... In general, it was clear that the US has not been successful in the past in promoting equality in health because of the social factors that influence health. Most of the exhibits showed some form of poverty that influenced the health of each class.*

Indeed, this structural inequality is the foundation upon which American society is built. Ironically, this is the very thing that simultaneously undermines health and human rights and precludes their widespread recognition.

Students’ comments within this theme demonstrate the presence of ideological and experiential barriers to meaningful engagement with health and human rights concepts and approaches. Such meaningful engagement requires that students first address their preconceived notions of the world they live in, by recognizing the grave injustices that regularly go unnoticed and unacknowledged. This is no small feat, for it requires an awareness of mundane injustices and the ability to recognize one’s entanglement in these injustices and to situate them within broader historical and political frameworks.<sup>31</sup> Second, students must recognize their own position of privilege and the ways in which they are implicated (even passively) in the suffering and exclusion of others. We recognize, of course, that privilege is relative and that undergraduate students in the United States (and across the world) may come from disenfranchised backgrounds. Nevertheless, an undergraduate education, especially from an elite university, affords a level of privilege that must be recognized and confronted in order to understand the complexities of inequality in a meaningful way. These realizations are necessary for any resistance to the status quo.<sup>32</sup>



For undergraduates to recognize the connection between their own privilege in relation to violations of the rights of others, it requires unlearning their unquestioned and widely believed narratives about themselves and the world around them. In the following section, we reflect further on the challenges in teaching health and human rights to undergraduates in the United States, and propose some tangible suggestions to overcoming these challenges.

## Conclusion

Although not all topics engaged our students equally, the CDC's exhibition helped us highlight the ways in which ongoing struggles with racism and structural inequality in the United States are embodied in the lives of individuals and communities. Situating these violations within a historical framework and linking them to human rights discourse and activism may help students see progress and possibilities for change in their own lives. Moreover, the exhibition illustrated the myriad possibilities within the struggle for human rights—the conflicting discourses and the possibilities for success.<sup>33</sup> In doing so, it helped illustrate the ways in which human rights laws are constantly translated into tangible collective activism.

While the exhibition helped our students recognize the immense scope of human rights violations in the United States, it is difficult to teach undergraduates the complexities of health and human rights on a global scale. It is a struggle to avoid a narrow focus on terrible atrocities or heroic narratives of sociopolitical action. Further, it is difficult to teach this topic without seeming to proselytize our belief in the right to health or take advantage of the power asymmetry that exists between teacher and student. In response to such difficulties, some educators have called for the use of an online or distance learning approach to balance this power differential and to engage students from a variety of backgrounds.<sup>34</sup> Despite the advantages of such an approach, it does not address the fact that the right to health refers not to an existing entitlement, but to an aspirational claim with normative and moral dimensions: people

do not have the material prerequisites to achieve their highest levels of health, but they *should*. These claims have inspired ongoing political struggles and achieved tangible gains, some which now seem mundane and are taken for granted.

Perhaps this is why the exhibits on HIV/AIDS and the grievous injustices visited upon gay men and people of color caught so few students' interest. The fact that our students were not compelled by this historic example was surprising to us. Although it is difficult to conjecture on the absence of findings, it is worth noting that most of our students ranged from 18 to 22 years in age—born long after the peak of the AIDS epidemic in the United States, and political struggle, policy shifts, and biomedical advances has since helped transform HIV/AIDS from a rapidly fatal condition to a preventable and manageable chronic disease. Acceptance and stigma of the LGBTQ community has changed dramatically in their lifetime. Students in high school and universities have been a common target of successful interventions to reduce HIV-related stigma.<sup>35</sup> Oral HIV pre-exposure prophylaxis (PrEP) is gaining availability and acceptability in the United States, especially among university students.<sup>36</sup> These advancements were borne of the activism of Jonathan Mann, who successfully deployed the human rights framework to destigmatize people and communities stricken by HIV and to prioritize HIV-related research and treatment. Ironically, we believe that it was the very *success* of health and human rights activism that made the suffering associated with HIV/AIDS seem like a historical relic or a lackluster example for most of our students.

In contrast, the examination of the intersection of racism, reproductive rights, and structural violence was successfully illustrated with the example of the eugenics movement and forced sterilization. This example may have been more salient because it directly challenged the discourse of American rectitude, which many of our students had not questioned. Although we have discussed human rights violations in the context of United States history and American exceptionalism, we believe that this applies in other settings. Confronting local human rights violations allows students to grapple with the



ways in which societies fall short of their espoused ideals and to learn about the health consequences of these violations. Our students were able to draw direct parallels between some of the historical case studies presented in the exhibition and contemporary issues and ongoing rights violations in the United States. For instance, our student's observation that "racism can bleed into every aspect of life and influence health" is a prevalent theme throughout US history, one that can be linked to contemporary debates such as mass incarceration and income inequality. Less emphasized in popular discourse, and what we can illustrate to our students, is the way in which these structural inequalities are reflected in health disparities.

This, we believe, represents the most promising opportunity to demonstrate the salience of the human rights discourse to undergraduate students in the United States. Our students vacillated between normalizing discrimination and inequality as inherent to the human condition, and wanting to *do something*. Helping them to realize that discrimination and marginality are constantly produced and reproduced by human actors and are therefore always evolving and contested was the most fruitful part of the course and the CDC exhibition. We would therefore recommend the use of the online version of the exhibit, along with case studies that they could link to ongoing human rights violations in the United States. For instance, students may be given a contemporary case study of a human rights violation in the United States and assigned to research the historical and political conditions that enabled the violation and the effects of such violations on population health. To highlight the possibilities for the human rights framework to affect social change, students may also be assigned to research the efforts of activists to resist such violations at the local, national, and international levels. Finally, students may be asked to compare and contrast their case study with other examples presented in the online exhibition. There is no shortage of these contemporary case studies, but examples include: the Flint water crisis; the detention of children and separation of families in immigration detention centers; the use of solitary

confinement in US prisons; and racially targeted referrals of drug-addicted pregnant women for arrest and prosecution for child abuse (see, for example, *Ferguson v. City of Charleston*).

Challenges remain in conveying the complexities of health and human rights and its possibilities as a tool of social change and political transformation. Although our students recognized important "wins" in the struggle for health and human rights in the United States, they expressed confusion and ambivalence towards a human rights-based approach to health. Rather than conveying this ambivalence as a weakness or as something indicative of irreconcilable internal contradictions, we seek to highlight the mutability of the human rights discourse, activism, and social change as sources of dynamism that fuels the transformative possibilities that underlie claims of the human right to health. By illustrating the ways in which different people with divergent backgrounds and worldviews across time and space can ground themselves within a human rights discourse, we can challenge structurally based rights violations in the United States and demonstrate to our students the richness and possibilities of a human rights-based approach to health. This, we believe, will not influence students' worldviews, but will give them tools to understand and engage with the world around them as they progress in their education and in their careers.

## References

1. A.R. Chapman and B.J.H.R.Q. Carbonetti, "Human rights protections for vulnerable and disadvantaged groups: The contributions of the UN Committee on Economic, Social and Cultural Rights," *Human Rights Quarterly* 33/3 (2011), pp. 682-732; A.E. Yamin, "Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care," *Health and Human Rights* 10/1(2008), pp. 45-63.
2. G. MacNaughton, "Untangling equality and non-discrimination to promote the right to health care for all." *Health and Human Rights* 11/2 (2009), pp. 47-63; NESRI (National Economic and Social Right Initiative). Available at <https://www.nesri.org/programs/what-is-the-human-right-to-health-and-health-care>.
3. T. Bul et al., *Reflection in global health* (San Francisco: Global Health Collaborations Press, 2016); B. Astle et al, *Global Health Education Competencies Tool-Kit*. Available

at <https://www.cugh.org/sites/default/files/CUGH%20Global%20Health%20Toolkit%20Web%20Version.pdf>.

4. J. Donnelly, *Universal human rights in theory and practice*. (New York: Cornell University Press, 2013); B. Oomen, Barbara. *Rights for others: The slow home-coming of human rights in the Netherlands* (Cambridge University Press, 2014).

5. S. Khoja-Moolji, "Producing neoliberal citizens: critical reflections on human rights education in Pakistan," *Gender and Education* 26/2 (2014), pp. 103-118; S. Khoja-Moolji, "The making of humans and their others in and throughout transnational human rights advocacy: exploring the cases of Mukhtar Mai and Malala Yousafzai," *Signs: Journal of Women in Culture and Society* 42/2, pp. 377-402; A. Osler, "Human rights education, postcolonial scholarship, and action for social justice," *Theory and Research in Social Education* 43/2 (2015), pp. 244-274.

6. M. Zembylas, "Critical pedagogy and emotion: working through 'troubled knowledge' in posttraumatic contexts," *Critical Studies in Education*, 54/2 (2013), p. 176-189; L. Worsham, "Going postal: Pedagogic violence and the schooling of emotion." In *Beyond the corporate university*, edited by H. Giroux and K. Myroides, pp. 229-265 (New York: Rowman and Littlefield, 2001).

7. A. Osler, "Human Rights Education, Postcolonial Scholarship, and Action for Social Justice," *theory and research in social education*, 43/2 (2015), pp. 244-274; F. Tibbitts and HS.R. Katz, "Dilemmas and hopes for human rights education: Curriculum and learning in international contexts," *Prospects*, 74/1-2 (2017), pp. 31-40; K.W. Yang, "Afterword: will human rights education be decolonising?" In *Bringing Human Rights Education to US Classrooms: Exemplary Models from Elementary Grades to University*, edited by S.R. Katz and A. McEvoy Spero, p. 225-235 (New York: Palgrave Macmillan, 2015); A.E.C. Struthers, "Teaching British values in our schools: but why not human rights values?" *Social and Legal Studies* 26/1 (2017), pp. 89-110; M. Zembylas, "Re-contextualising human rights education: Some decolonial strategies and pedagogical/curricular possibilities," *Pedagogy, Culture and Society* 25/4 (2017), pp. 487-499; M. Zembylas and A. Keet, *Critical human rights, citizenship, and democracy education: Entanglements and regenerations* (New York: Bloomsbury Critical Education, 2018).

8. Centers for Disease Control and Prevention, *Health Is a Human Right: Race and Place in America*, L.E. Shaw, Editor (2013), Centers for Disease Control and Prevention David J. Sencer Museum: Atlanta, Georgia.

9. R. Burnham and E. Kai-Kee, *Teaching in the art museum: Interpretation as experience*. (New York: Getty Publications, 2011); R. Burnham and E.J.J.o.A.E. Kai-Kee, "The art of teaching in the museum," *The Journal of Aesthetic Education* 39/1 (2005), pp. 65-76.

10. See also: The National Library of Medicine, "Against All Odds: Making a Difference in Global Health (2008-

2010). Available at <https://www.nlm.nih.gov/exhibition/againsttheodds/exhibit/index.html>; The Advocates for Human Rights, "The Right to Health: Equal Access to Health Care in the United States." Available at [https://www.theadvocatesforhumanrights.org/uploads/right\\_to\\_health\\_care\\_lesson\\_plan.pdf](https://www.theadvocatesforhumanrights.org/uploads/right_to_health_care_lesson_plan.pdf).

11. D.R. Hill, R.M. Ainsworth, and U. Partap, "Teaching global public health in the undergraduate liberal arts: A survey of 50 colleges," *American Journal of Tropical Medicine and Hygiene* 87/1 (2012), pp. 11-15; J.P. Koplan, and R.L. Baggett, "The Emory Global Health Institute: developing partnerships to improve health through research, training, and service," *Academic Medicine* 83/2 (2008), pp. 128-133; L. Hanson, "Global citizenship, global health, and the internationalization of curriculum: A study of transformative potential," *Journal of Studies in International Education* 14/1 (2008), pp. 70-88.

12. P. Brown, and S. Closser, *Foundations of global health: An interdisciplinary reader* (New York: Oxford University Press, 2018).

13. United Nations General Assembly, *International Declaration of Human Rights*. 1948, United Nations General Assembly: New York.

14. Ibid.

15. J. Mann, "Human rights and the new public health," *Health and Human Rights* 1/3 (1995), pp. 229-233; P. Farmer, "Pathologies of power: Rethinking health and human rights," *American Journal of Public Health* 89/10 (1999), pp. 1486-1496.

16. S. Gruskin, E.J. Mills, and D. Tarantola, "History, principles, and practice of health and human rights," *The Lancet*, 370/9585 (2007), p. 449-455; P. Rosenblum, "Teaching human rights: ambivalent activism, multiple discourses, and lingering dilemmas," *Harvard Human Rights Journal* 15 (2002), pp. 301-308; S.E. Merry, "Measuring the world indicators, human rights, and global governance," *Current Anthropology* 52/S3 (2011), pp. S83-S95; S.E. Merry, "Human rights law and the demonization of culture (and anthropology along the way)," *Political and Legal Anthropology Review* 11/2, pp. 47-63.

17. P. Farmer, "Pathologies of power: rethinking health and human rights," *American Journal of Public Health* 89/10 (1999), pp. 1486-1496; E. Fee, and M. Parry, "Jonathan Mann, HIV/AIDS, and Human Rights," *Journal of Public Health Policy*, 29/1 (2008), p. 54-71; H. Hestermeyer, Human rights and the WTO: the case of patents and access to medicines (New York/Oxford: Oxford University Press, 2007); M. Heywood, "South Africa's treatment action campaign: combining law and social mobilization to realize the right to health," *Journal of Human Rights Practice* 1/1 (2009), pp. 14-36.

18. C.E. Anderson, *Eyes off the prize: the United Nations and the African American struggle for human rights, 1944-1955* (Cambridge: Cambridge University Press, 2003).

19. L. Gable, "The Patient Protection and Affordable Care Act, public health, and the elusive target of human rights." *The Journal of Law, Medicine, and Ethics* 39/3 (2011), pp. 340-354.
20. H.R. Bernard, *Research methods in anthropology: qualitative and quantitative approaches*. (New York: Rowan and Littlefield Publishers, 2017).
21. E. Black, *War against the weak: Eugenics and America's campaign to create a master race*. (New York: Four Walls Eight Windows, 2003); C.P. Kendregan, "Sixty years of compulsory eugenic sterilization: three generations of imbeciles and the constitution of the United States." *Chicago-Kent Law Review* 43/2 (1966), pp. 123-143.
22. E. Black, *War against the weak: Eugenics and America's campaign to create a master race*. (New York: Four Walls Eight Windows, 2003).
23. Office of the United Nations High Commissioner for Human Rights, *Sexual and Reproductive Health and Rights*. Available at <http://www.ohchr.org/EN/Issues/Women/WRGS/Pages/HealthRights.aspx>.
24. A.M. Stern, *Eugenic nation: faults and frontiers of better breeding in modern America*. (Berkeley: University of California Press, 2015); L. Ko, *Unwanted sterilization and eugenics programs in the United States*. *Independent Lens* 2016. Available at <http://www.pbs.org/independentlens/blog/unwanted-sterilization-and-eugenics-programs-in-the-united-states/>.
25. S.S. Willen et al., "Syndemic vulnerability and the right to health," *The Lancet* 389/10072 (2017), pp. 964-977; S. Gloppen, "Litigation as a strategy to hold governments accountable for implementing the right to health," *Health and Human Rights* 10/2 (2008), pp. 21-36.
26. B. Salhi and P. Brown. "Rudolf Virchow," *International Encyclopedia of Anthropology* 2018. Available at <https://onlinelibrary.wiley.com/doi/full/10.1002/9781118924396.wbiea1568> DOI: 10.1002/9781118924396.wbiea1568; W.E.B. DuBois, *Souls of black folk*. (Hayes Barton Press, 1965).
27. G. Oppenheimer et al. "Health and human rights: Old wine in new bottles?" *The Journal of Law, Medicine & Ethics* 30/4 (2002), pp. 522-532; A. Keet, "It is time: Critical Human Rights Education in an age of counter-hegemonic distrust," *Education as Change* 19/3 (2015), pp. 46-64.
28. C.E. Easley, S.P. Marks, and R.E. Morgan, Jr., "The challenge and place of international human rights in public health," *American Journal of Public Health* 91/12 (2001), pp. 1922-1925.
29. C. De Albuquerque, *Realising the human rights to water and sanitation: A Handbook by the UN Special Rapporteur*. Available at <https://unhabitat.org/books/realising-the-human-rights-to-water-and-sanitation-a-handbook-by-the-un-special-rapporteur-catarina-de-albuquerque/>
30. N. Gaber, "Mobilizing health metrics for the human right to water in Flint and Detroit, Michigan," *Health and Human Rights* 21/1 (2019), pp. 179-189.
31. M. Zembylas, "Critical pedagogy and emotion: working through 'troubled knowledge' in posttraumatic contexts," *Critical Studies in Education*, 54/2 (2013), p. 176-189; L. Worsham, "Going Postal: Pedagogic Violence and the Schooling of Emotion." In *Beyond the Corporate University*, edited by H. Giroux and K. Myroides, pp. 229-265 (New York: Rowman and Littlefield, 2001).
32. A.E. Yamin, "Shades of dignity: exploring the demands of equality in applying human rights frameworks to health," *Health and Human Rights* 11/2 (2009), pp. 1-18; A.E. Yamin. *Power, Suffering, and the Struggle for Dignity: Human Rights Frameworks for Health and Why They Matter*. (Philadelphia: University of Pennsylvania Press, 2017).
33. S. Willen, "Health is a human right—at CDC?" *Health and Human Rights* 21/1 (2019), pp. 163-177.
34. M. Bajaj, "Human rights education: ideology, location, and approaches," *Human Rights Quarterly*, 33/2 (2011), pp. 481-508; F. Tibbitts, "Evolution of Human Rights Education Models," in *Human Rights Education: Theory, Research, Praxis*, edited by M. Bajaj, pp. 69-95 (Philadelphia: University of Pennsylvania Press, 2017).
35. A.L. Stangl, J.K. Lloyd, L.M. Brady, C.E. Holland, and S. Baral, "A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: how far have we come?" *Journal of the International AIDS Society*, 16/S2 (2013), pp. 18,734-18,748.
36. A.E. Petroll, J.L. Walsh, J.L. Owczarzak, T.L. McAuliffe, L.M. Bogart, and J.A. Kelly. "PrEP awareness, familiarity, comfort, and prescribing experience among US primary care providers and HIV specialists," *AIDS and Behavior* 21/5 (2017), pp. 1256-67; T. Arnold, C.E. Sims-Gomillia, K. Portz, E. Bologna, and B. Williams, "Preliminary investigation evaluating college students' willingness and need to take pre-exposure prophylaxis (PrEP) for HIV," *HIV & AIDS Review. International Journal of HIV-Related Problems* 17/2 (2018), pp. 98-102.

# Tomorrow's Stewards: The Case for a Unified International Framework on the Environmental Rights of Children

KAREN E. MAKUCH, SUNYA ZAMAN, AND MIRIAM R. ACZEL

## Abstract

This paper evaluates an approach for strengthening environmental rights for children to safeguard child health. We focus on children as beneficiaries of environmental rights on account of their vulnerability to environmental impacts on their physical and mental health. Current legal frameworks, unless explicitly identifying children as beneficiaries, arguably tend to be adult-centric. Our goal here is to develop a comprehensive rights-based framework to ensure that children are protected against adverse environmental impacts. We argue that approaches that safeguard children's rights to life, health, and education should include environment-related issues, standards, and protections for those rights to be fully implemented. We propose employing sustainable development as a framework under which to develop an international treaty to promulgate the environmental rights of the child, thereby promoting health, environmental stewardship, and quality of life for children and future generations. We further argue that children's environmental rights extend beyond basic "needs"—such as clean air, clean water, sanitation, and a healthful environment, among others—to include the right to benefit from access to nature of a certain quality and the wealth of educational, recreational, developmental, and health benefits that come with ensuring protection of the environment for children.

---

KAREN E. MAKUCH is a lecturer in environmental law at the Centre for Environmental Policy, Imperial College, London, UK.

SUNYA ZAMAN is a PhD student and research assistant at the School of Community and Regional Planning, University of British Columbia, Vancouver, Canada.

MIRIAM R. ACZEL is a President's Scholar PhD candidate at the Centre for Environmental Policy, Imperial College, London, UK, and co-director of the Aczel Foundation for Research and Education in Science and Mathematics.

Please address correspondence to Karen E. Makuch. Email: [k.e.makuch@imperial.ac.uk](mailto:k.e.makuch@imperial.ac.uk).

Competing interests: None declared.

Copyright © 2019 Makuch, Zaman, and Aczel. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted noncommercial use, distribution, and reproduction in any medium, provided the original author and source are credited.



## Introduction

As children face increasing ecological and social challenges, such as pollution, health risks, climate change, land degradation, poverty, and lack of access to education, among others, advancing environmental human rights has never been more important. Further, a growing body of research that links reduced exposure or time spent outdoors to a decline in child mental well-being adds urgency to our argument.<sup>1</sup> The adverse impacts of environmental degradation breach both environmental and human rights.<sup>2</sup> Given that children have historically suffered from underrepresentation in environmental protection, an approach based on human rights may bring benefits in environmental advocacy.<sup>3</sup> Though not all stakeholders are morally compelled to implement the environmental rights of children, we concede that some form of human rights-based legislation would arguably make it difficult for “offenders” to sidestep the moral obligation to safeguard the health and environmental well-being of children.<sup>4</sup>

Environmental rights, as defined by the United Nations Environment Programme, include both substantive and procedural rights.<sup>5</sup> Substantive rights “include those in which the environment has a direct effect on the existence or the enjoyment of the right itself” and include both civil and political rights, as well as cultural and social rights, such as the rights to “health, water, food, and culture in addition to collective rights affected by environmental degradation,” including indigenous peoples’ rights.<sup>6</sup> Procedural rights represent an important intersection between human rights law and environmental law, as they prescribe actions that states must take to enforce legal rights. They include access to information and participation in decision-making, access to justice, and other rights.<sup>7</sup> Environmental rights can also be a useful precursor to safeguarding the health of children, particularly in the absence of a sound environmental regulatory framework.

For our purposes, we define a child in accordance with article 1 of the United Nations Convention on the Rights of the Child, which

states that “a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier.”<sup>8</sup> Typically, children have not been independently or explicitly represented or considered in the setting of environmental standards, environmental law-making, or environmental rights discourse, yet they are its victims.<sup>9</sup>

We present five arguments in this paper:

1. Much of the multilateral legislation designed to address environmental issues ought to benefit the child as a distinct recipient, particularly if interpreted and applied purposefully with the child in mind, resulting in improved standards of health and well-being for the child and increased environmental protection and standards.
2. Children would benefit from higher environmental standards than those currently prescribed in international legal instruments, given that they are physiologically more vulnerable than adults to environmental pollution and other adverse environmental impacts.<sup>10</sup>
3. More concerted action is needed to safeguard the health of children relative to substantive environmental measures (such as access to clean water).<sup>11</sup>
4. Providing children with environmental rights is a prerequisite to attaining sustainable development in the future as adults.
5. There are currently no international standards (and very few national ones) on the environmental rights of the child per se.

## Background: Sustainable development as a framework for the environmental rights of children

The 1987 Brundtland Commission report, *Our Common Future*, articulated the concept of sustainable development within the international community, making explicit reference to “needs”:

*Humanity has the ability to make development sustainable to ensure that it meets the needs of the present without compromising the ability of future*



*generations to meet their own needs. The concept of sustainable development does imply limits—not absolute limits but limitations imposed by the present state of technology and social organization on environmental resources and by the ability of the biosphere to absorb the effects of human activities.*<sup>12</sup>

Furthermore, chapter 25 of the 1992 United Nations Conference on Environment and Development's nonbinding "action plan," or Agenda 21, specifically addresses children and youth in sustainable development. We argue that the health and well-being of current and future generations ought to be the focal point of any current legislation or policy developments that promote sustainability and positive environmental protection for the needs of children.<sup>13</sup> Children *need* to breathe clean air. Children *need* clean drinking water. Children *need* access to nature because of its benefits for health and well-being. We interpret the concept of needs within the spirit of the Brundtland Commission, as this provides a useful link between human rights and environmental objectives, so that children might have lives of a certain environmental quality.

Dominic McGoldrick suggests that "sustainable development can be structurally conceived as having a [three-] pillared, temple-like structure composed of international environmental law, international human rights law and international economic law ... The emergence of sustainable development has coincided with a broadly increasing consensus in international human rights."<sup>14</sup> This interpretation of sustainable development aligns with our arguments for the environmental rights of children, as the attainment of human rights standards is contingent on the attainment of sustainable development standards, and vice versa.

Further, it can be argued that we have seen a revival of the link between human rights and the environment over the past few decades, spearheaded by regulatory and policy developments related to climate change (for example, the 2015 Paris Agreement).<sup>15</sup> We are now seeing children striking from school to campaign against perceived inaction on climate change, as well as children suing governments for failure to respond to pressing climate needs, bolstered by support from the United

Nations (UN) Special Rapporteur on human rights and the environment.<sup>16</sup> The international community is awakening to the notion of children as environmental actors and stakeholders.

## Defining environmental rights

Environmental rights are important for securing the health of future generations, as they protect basic necessities needed for survival and to thrive, such as water and air.<sup>17</sup> If we allow others to profit from polluting our natural resources at the expense of causing ill-health, there is inequity and needs cannot be met.<sup>18</sup>

We adopt an anthropocentric interpretation of environmental rights in order to treat a "decent," "healthy," "healthful," "clean," or "sound" environment as an economic and social right.<sup>19</sup> This interpretation fits within our working framework of sustainable development, which requires developmental objectives to take cognizance of environmental, social, and economic matters. Sustainable development allows us to argue against uncontrolled and unaccountable environmental exploitation in order to meet the needs of the current generation, a large subgroup of which are children, while not environmentally, socially, or economically compromising the needs of future generations. According to the UN Special Rapporteur on human rights and the environment, a "safe, clean, healthy and sustainable environment is integral to the full enjoyment of a wide range of human rights, including the rights to life, health, food, water and sanitation. Without a healthy environment, we are unable to fulfil our aspirations or even live at a level commensurate with minimum standards of human dignity."<sup>20</sup> This anthropocentric definition portrays the environment as something that needs to be protected in order to be either readily or eventually available, accessible, and utilizable by humans.<sup>21</sup> In the context of this work, we offer the standard of environment as being one that is "healthful": healthy in its own integral way, but giving of health to others, including children.

## The Convention on the Rights of the Child

At the international level, the legal basis that is most appropriate for our arguments concerning the environmental rights of children is the 1989 United Nations Convention on the Rights of the Child.<sup>22</sup> Currently, 196 countries are parties to the treaty, meaning that they agree to the legal restrictions and principles stated in the document. Although the convention does not explicitly mention environmental rights as a type of right, it does recognize environment-related rights.<sup>23</sup> Such rights can be argued to be encompassed by the following articles: article 2 (discrimination), article 16(1) (privacy, family, home), article 24 (health, water, environmental pollution, food), article 27(1) (social development), and article 29(1)(e) (respect for the environment). Four further articles include article 6 (development of child), article 22 (refugee child protection), article 23 (disabled children), and article 28 (education). Article 6 on the right to life provides the most substantial legal argument for the environmental rights of the child. If you cannot breathe clean air, drink clean water, and so on, how can you live? Further, articles 23 and 24 indicate that children should be given sufficient health care for survival and development, including special provisions for children with disabilities, again providing convincing reasons to demand some form of environmental safeguards for children to avoid ill health or barriers to a full life due to environmental concerns. Articles 28 and 29 endorse children's educational rights and develop educational goals that help children learn how "to live peacefully, protect the environment and respect other people."

Article 27 provides a convincing legal basis for the promotion of the environmental rights of the child. Article 27(1) requires state parties to "recognise the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development." Current literature supports our assertion that promoting a child's environmental rights is necessary to ensure the child's physical, mental, spiritual, moral, and social development.<sup>24</sup> When the results of such studies are applied to article 27(1) of the convention, we can argue that the promulgation of environmental rights

and protection by state parties can advance the standards of living and development of the child. Fatma Zohra Ksentini, in her UN report on human rights and the environment, argues that the convention's articles outline environmental elements in the form of a child's rights to life, health, an adequate standard of living, and education.<sup>25</sup>

The Convention on the Rights of the Child has been rapidly ratified by most of the world's countries, providing evidence of global interest in protecting children's rights *per se*.<sup>26</sup> Thus, the introduction of children's environmental rights could prove to be readily accepted worldwide, given the mounting international support for sustainable development and environmental protection (support for the 2015 Paris Agreement and the revised 2015 Sustainable Development Goals have encouraged the participation of youth in achieving the 17 Sustainable Development Goals).<sup>27</sup> States have already agreed on working definitions and standards on the "environment" in various multilateral environmental agreements. However, the Convention on the Rights of the Child enshrines rights that are *related* to environmental issues yet are not specifically designed to address the environmental rights of children.

## Cross-border environmental problems and rights-based problems for children

Environmental issues frequently have a transnational reach.<sup>28</sup> For example, the "slash and burn" fires that were deliberately started to clear land for agricultural purposes in Indonesia resulted in air pollution in Malaysia, Singapore, Thailand, and the Philippines. With respect to human rights agreements, the application of the Convention on the Rights of the Child tends to be geographically confined to those state parties that are legally required to protect children within their own jurisdictions.<sup>29</sup> Environmental pollution or natural and human-induced disasters can harm children living in neighboring countries, yet the substantive provisions of the convention are arguably not interpreted widely enough to safeguard children beyond states' national jurisdictions. This is counter to the con-

vention's aim to protect the rights of the children of this planet as a whole.

### *Recommendations for strengthening the framework*

State parties to the Convention on the Rights of the Child need to be open to providing assistance to children of neighboring countries rather than operating solely in their own countries. This could be done by amending articles to include the protection of children who are affected by transboundary environmental harm. The development of bilateral legislation to address the adverse effects of cross-border environmental harm on children, drawing on relevant multilateral environmental agreements, such as the Convention on Environmental Impact Assessment in a Transboundary Context, would be useful.<sup>30</sup> One pressing issue, for example, is air pollution, which would also require precise language concerning countries and their borders, particularly borders with a history of conflict (such as the India-Pakistan border and the Israel-Palestine border) and clauses on the cooperation of the wider international community. This inclusion could result in a comprehensive approach to the protection of children's environmental rights in which countries work together to promote the well-being of their children and the global commons and to implement the environmental principles of good neighborliness and cross-border cooperation, among others. This cooperative approach would allow competent authorities to share best practices and resources and allow collaborative thinking among local planners, environmental regulators, and child rights advocates based on rights and equity. Some of the environmental rights-based issues that could be addressed through such cooperation are discussed below.

### Access to healthful nature for physical and mental health

Children's access to the natural environment varies around the world. Certain areas either lack green spaces altogether or have spaces that are polluted and hazardous to children's well-being and develop-

ment.<sup>31</sup> For many children, the natural environment is not a recreational space for leisure activities but instead a place that demands intense physical labor due to poverty.<sup>32</sup> Furthermore, children living in developing countries may deal with unsafe and unsanitary conditions, food insecurity, war, and natural disasters.<sup>33</sup> Disproportionate access to clean green spaces and exposure to environmental hazards can also stem from structural inequalities based on race, socioeconomic status, and gender.<sup>34</sup> A recent study conducted by Catherine Walker sheds light on the discrepancies between children's perspectives of the environment in India and the United Kingdom.<sup>35</sup> According to Walker, children's views differed based on the prevalence of their exposure to such hazards, geographical proximity to these hazards, and the steps taken to mitigate them. Such environmental inequalities may benefit from strengthening the application of existing human rights and working to dismantle structural inequalities by adopting an environmental justice lens. Additionally, Kim Ferguson et al. claim that the documented impacts of the physical environment on children's development in the Global South are limited and should be investigated in collaboration with children, government agencies, and community members.<sup>36</sup>

In some parts of the world, children are increasingly less connected with the environment's healthful and health-giving qualities. Children may have access to certain types of natural areas, but these areas may not be healthful—for example, contaminated land sites or fields containing pesticides. There may be an absence of green spaces or a lack of access to such spaces due to social, economic, and other reasons.<sup>37</sup> Growing evidence suggests that a child's disconnection with nature prevents healthy mental and physical development, as well as responsible stewardship of the environment.<sup>38</sup>

### Nature deficit disorder and the link to children's health

Richard Louv's idea of "nature deficit disorder" contends that children's "alienation from nature" can result in "diminished use of the senses, atten-

tion difficulties and higher rates of physical and emotional illnesses.”<sup>39</sup> Moreover, there is ample evidence to suggest that adult memories of childhood experiences have significant impacts on an adult’s emotional stability.<sup>40</sup> Exposure to nature at a young age helps children develop their emotional responsiveness, a quality that contributes to their emotional well-being during adulthood.<sup>41</sup> This further highlights the importance of the fact that the children of today will ultimately grow up to become the care-takers of the environment in the future. Studies have also shown that a child’s life course can have major impacts on adult life.<sup>42</sup> Examples include a study by Nancy Wells and Kristi Lekies, in which 2,000 adults were interviewed regarding their environmental childhood experiences and current attitudes toward the environment.<sup>43</sup> The results indicated a positive relationship between those who had participated in environmental activities as children and environmentally friendly behaviors as adults. Research by the United Nations Children’s Fund reveals that children’s learning abilities and behaviors are enhanced when they study outdoors and that their mental well-being and happiness grows with increasing exposure to nature.<sup>44</sup> Below, we present arguments for the environmental rights of children as a means to promote their reconnection to healthful nature.

#### Four key categories that benefit from environmental rights

*“Children are born with a sense of wonder and an affinity for Nature. Properly cultivated, these values can mature into ecological literacy, and eventually into sustainable patterns of living.”*<sup>45</sup>

Moving forward, we have divided “environmental rights” as they pertain to children into four categories, following research undertaken by the National Trust, a UK-based nongovernmental organization: (1) health and well-being; (2) education and awareness; (3) resilient communities; and (4) ecosystem services.<sup>46</sup>

These four categories are associated with children’s most basic rights: adequate health care,

an education that includes general awareness of global issues, resilience in the face of natural and human-induced disasters, and protected ecosystem services for inter-generational equity.<sup>47</sup> The studies we cite below tend to use examples from developed countries. This does not mean that the findings and arguments do not apply to children in developing-country contexts, but rather that relevant studies may not have been undertaken to date.

#### *Health and well-being*

Access to health-giving green spaces (safe, natural areas as opposed to polluted cities, for example) is known to increase outdoor activity, which in turn has the capacity to produce positive health-related outcomes.<sup>48</sup> Early exposure to outdoor activities leads to children following these habits during their adulthood, ensuring that they can become responsible future stewards of the environment.<sup>49</sup> Increased contact with nature can also improve mental well-being, which is a crucial aspect of a child’s physical development.<sup>50</sup>

However, many environments where children live either do not offer access to healthful green spaces or may be hazardous, polluted, or overgrown.<sup>51</sup>

#### *Education and awareness*

Increased exposure to the natural environment enhances a child’s learning abilities. Child psychologist Aric Sigman coined the term “countryside effect,” finding that increased contact with nature improves a child’s concentration, reasoning, observational skills, and overall academic performance.<sup>52</sup> According to the National Trust, a child experiences educational and developmental benefits in four impact categories: (1) cognitive, (2) affective, (3) interpersonal and social, and (4) physical and behavioral.<sup>53</sup> We argue that this can benefit the mental and physical health and development of the child.

#### *Resilient communities*

Children’s environmental rights can assist in building resilient communities.<sup>54</sup> Children who have had a strong connection with nature become adults who pass to their offspring positive traits ac-



quired from their exposure to the natural world.<sup>55</sup> Studies undertaken by researchers at the University of Leeds in the United Kingdom have shown that a parent's effort to raise positive environmental awareness in their children is more crucial than a school program in environmental education.<sup>56</sup> Additionally, children who are given an environmental education have a positive impact on their parent's environmental attitudes.<sup>57</sup>

With extensive studies providing evidence that climate change has led to an increasingly high rate of unpredictable disasters, it is critical that we understand how to alleviate the effects of climate change on children and future generations.<sup>58</sup> Such effects include floods, cyclones, earthquakes, droughts, tsunamis, and other extreme weather events, which have led to fatalities, displacement, poverty, food insecurity, and habitat destruction.<sup>59</sup> Implementing child rights programming in DRR planning should include the participation of children in identifying disaster relief solutions in times of emergency. This in turn, decreases chances of exploitation and improves overall resilience.<sup>60</sup> Contingency planning and crisis management can be ensured by acknowledging the environmental rights to education and awareness, access to clean drinking water, access to information, and so on. David Selby and Fumiyo Kagawa note the significance of including practical DRR-based knowledge in school curricula, as well as conducting awareness-raising campaigns in order to strengthen the response capabilities of communities.<sup>61</sup> Victor Marchezini et al. argue for the importance of involving youth and the education sector in participatory and community-based approaches to early warning systems.<sup>62</sup>

The 2004 Indian Ocean tsunami illustrates how organizations such as Save the Children have used educational strategies for DRR purposes. Students attending the Ban Talaynork School in Ranong, Thailand, were encouraged to participate in evacuation plans and were taught how to cope with tsunamis in their school curricula. They were also given psychosocial rehabilitation treatments to aid their emotional and psychological recovery.<sup>63</sup> Children also have the ability to orchestrate di-

aster relief strategies without outside help. In the flood-prevalent area of the Go Cong Dong district in Vietnam, children devised a plan to develop an evacuation road so that they would not lose access to their schools or playgrounds during typhoon season.<sup>64</sup> The fact that education and awareness can change a life-or-death situation indicates that such knowledge is not only an environmental right but also a basic human right.<sup>65</sup> Education as an emergency response can provide information on diseases and hygiene, another basic environmental and human need.<sup>66</sup> Encouraging meaningful youth participation in disaster planning—and supporting it through a robust framework for children's environmental rights protection—can provide a long-term investment for resilient communities given that the youth of today will be the ones implementing DRR initiatives and actions in the future.<sup>67</sup>

### *Ecosystem services*

Ecosystems are a major factor contributing to people's economic, cultural, and spiritual well-being.<sup>68</sup> A healthy ecosystem ultimately leads to healthy children, adults, and future generations, and vice versa.<sup>69</sup> Employing children's environmental rights—including the rights to education, food, shelter, clean water and air, and sanitation—can protect ecosystem services for current and future generations, bringing both ecocentric and anthropocentric benefits.<sup>70</sup> The Waipa Foundation in Hawaii empowers residents, especially those with low incomes, to manage their environmental resources efficiently, employing a traditional environmental management system that incorporates “sub-divisions of land, from mountaintop to seashore, using streams as boundaries through activities with the local community and school children.”<sup>71</sup> Growing organic food, educating children on environmental issues, and including them in environmental management strategies has helped protect ecosystem services, in turn providing a magnitude of co-benefits for children.<sup>72</sup>

However, these four categories are not currently present in international and national frameworks because children are largely not recognized as “stakeholders.” A framework that acknowledges



children as official stakeholders and gives them the right to be heard, the right to participate, and the right to decision-making is a necessary next step. Fortunately, there have been a few recent lawsuits related to environmental issues in which children have won the right to be heard. For example, a case in the Philippines (*Oposa v. Factoran*) allowed 43 children to be heard regarding their concerns over timber leases and consequential deforestation.<sup>73</sup> Similarly, the *Chernaik v. Kitzhaber* case in the United States is another hopeful example of children and youth being allowed to fight for their current and future well-being.<sup>74</sup> Other examples include the children of Quebrada de Alajuela in Ecuador, who pointed out that a bridge connecting their village to a neighboring one was not strong enough to handle a flood, consequently saving the community from a potentially disastrous safety hazard.<sup>75</sup>

Although there are many good examples of children being allowed to voice their opinions, there are also cases in which such rights have been disregarded. Therefore, promoting legal victories and informing the general public about them can provide a framework for similar lawsuits in the future. Furthermore, minors need effective guardians—that is, adults who are on the side of safeguarding the environmental rights of children. This is to make sure that in cases where children are considered to lack legal standing, they can be represented by advocates with access to the courts. Such advocates could be nongovernmental organizations, school teachers, or parents.

## Design and implementation

An internationally agreed framework for the environmental rights of children would benefit children and future generations in a multitude of ways. We propose utilizing sustainable development as a framework under which to develop an international treaty to promulgate the environmental rights of children, promoting health, environmental stewardship, and quality of life for children and future generations. Children's environmental rights extend beyond the most basic "needs"—clean air, clean water, sanitation, and healthy environment,

among others—to the right to benefit from access to nature and the wealth of educational, recreational, developmental, and health benefits that come with ensuring protection of the environment for children. As there are currently no prescribed standards on the environmental rights of children, we propose the development of an international framework to establish national and international minimum standards, leading to improved health, quality of life, and the enjoyment of basic children's rights. The framework could be structured similarly to the Paris Agreement, where signatories committed to reducing global greenhouse gas emissions, adapting to impacts of climate change, and providing financial assistance to developing countries affected by a changing climate.<sup>76</sup> Moreover, the framework could draw from the revised 2015 Sustainable Development Goals, which have encouraged the participation of youth in achieving the goals.<sup>77</sup>

For those who believe the existing multilateral environmental agreements or human rights agreement would render such a framework redundant, we remind the reader that there is currently no international agreement that sets the standard for children per se as the beneficiaries of global environmental standards, rights, and safeguards.

## Advocacy

There is arguably a need for national movements to progressively augment international lawmaking in the area of children's environmental rights. The first step in achieving such a movement requires the involvement of proactive citizens to encourage national governments to represent children at international negotiations. However, in order to ensure that citizens are proactive, effective dialogue must occur between them and their national governments.<sup>78</sup> According to James Blake, tensions have arisen among the various stakeholders involved in environmental rights protection due to the "value-action gap," when people do something different than what they said they would do.<sup>79</sup>

Representation is different from participation with respect to political movements. There

have been cases where national governments have empowered children to voice their concerns over social issues during parliamentary hearings and consultative processes on policy.<sup>80</sup> In most of these cases, children do not have the right to exercise political power. India, however, allows children to exercise political power through children-based parliaments that were established in the 1990s.<sup>81</sup> Here, child representatives have made changes to improve educational policies and incorporate better community services in their villages.<sup>82</sup> Success stories like these can be a good model for other countries, even if not all countries have the same capacity to establish child parliaments. Thus, the first step is for citizens to be more responsive to the needs of children, ensuring that their power, struggles, and vulnerabilities are taken into account and recognized as “diverse social experiences.”<sup>83</sup> Through citizens’ response to the diverse experiences of children, governments can be influenced to represent children and develop agreements that address their specific needs.

The international community also has a responsibility to all children and not just those within their borders. To this end, the global commons should work together for the effective implementation of said agreement. Here, we can employ established principles of environmental law, such as the principle of common but differentiated responsibilities, again mirroring the Paris Agreement, with nations working collectively to equitably create and implement environmental rights for children. Countries that have historically caused more environmental harm (from which they have benefitted economically) would provide economic and capacity-building support to nations that are facing challenges, yet the environmental rights of children would be the common objective: reasserting moral obligations toward current and future generations of children, while also benefitting the environment. This approach demands the practical implementation of measures at the national level, investment, and regular monitoring and reporting on measures and standards. A central international secretariat could oversee progress, requiring reports of health-related data correlated with environmen-

tal measures, for example. To save resources at the national level, the national competent reporting authority could be the same body that reports to other relevant supranational organizations, such as the World Health Organization. Nongovernmental organizations and civil society groups could play a role as well, in the absence of national political will.

## Concluding recommendations

One of the first steps is to incorporate children’s environmental rights within every country’s political agenda by adding well-defined *environmental rights for children* as separate provisions in laws and policies. Furthermore, the policy recommendations outlined above can be effectively implemented only through collaborative awareness and funding. One of the ways in which funding can be secured is by taxing the corporations that directly or indirectly cause harm to children through their unsustainable practices. This would require regulatory monitoring and enforcement, as companies may arguably avoid taxes and accountability for their actions through tax havens, transfer pricing, and other loopholes in existing policies.<sup>84</sup> Rules could be enforced through the suspension of licenses, prosecutions, legal instruments, and community pressure.<sup>85</sup> It should be noted that community pressure would require communication among a myriad of stakeholders to endorse a truly interdisciplinary approach to children’s environmental rights protection. Where public funds are lacking, there are some organizations that can help fund international children-related projects through private and philanthropic investment. Examples of these organizations include the Education for Development Foundation, Child Health Foundation, and the Global Fund for Children, which aim to support initiatives proposed by nongovernmental organizations and the general public.<sup>86</sup>

International awareness should urgently be promoted through campaigns targeted toward guardians of children (this can include children themselves, parents and caregivers specifically, and schools, politicians, and communities more widely) in order to demonstrate how environmental harm

directly affects children. Awareness raising would not only enhance children's connection with nature by rooting it within local social and cultural contexts but also help the wider international community move toward a future that promotes the protection of children's environmental rights. Thus, it is through positive development, whether through nature or nurture, that the children of today can enjoy their environmental rights and ensure the same for the children of tomorrow.

## References

1. R. Louv, *Last child in the woods: Saving our children from nature-deficit disorder* (Chapel Hill, NC: Algonquin Books, 2005).
2. A. Dobson, *Citizenship and the environment* (Oxford: Oxford University Press, 2003).
3. T. Kerns, "Ten practical advantages of a human rights approach to environmental advocacy," *Journal of Environmental Studies and Sciences* 3/4 (2013), pp. 416–420.
4. *Ibid.*
5. United Nations Environment Programme, *What are environmental rights?* Available at <https://www.unenvironment.org/explore-topics/environmental-rights-and-governance/what-we-do/advancing-environmental-rights/what>.
6. *Ibid.*
7. *Ibid.*
8. Convention on the Rights of the Child, G.A. Res. 44/25 (1989), art. 1.
9. Convention on the Rights of the Child, G.A. Res. 44/25 (1989); K. E. MacDonald (Makuch), "Sustaining the environmental rights of children: An exploratory critique," *Fordham Environmental Law Review* 18 (2006), pp. 1–65.
10. World Health Organization, *Effects of air pollution on children's health and development: A review of the evidence* (2005); European Commission DG Environment-funded study at the University of Brescia, "Monitoring air pollution effects on children for supporting public health policy: The protocol of the prospective cohort MAPEC study," *BMJ Open* 4/9 (2005).
11. United Nations Children's Fund, *The state of the world's children 2011: Executive summary* (2011).
12. G. H. Brundtland, *Our common future: Report of the 1987 World Commission on Environment and Development* (Oslo: United Nations, 1987), para. 27.
13. MacDonald (see note 9).
14. D. McGoldrick, "Sustainable development and human rights: An integrated conception," *International and Comparative Law Quarterly* 45/4 (1996), pp. 796–818.
15. A. E. Boyle and M. R. Anderson (eds), *Human rights approaches to environmental protection* (UK: Clarendon Press, 1996); D. Shelton, "Human rights, environmental rights, and the right to environment," *Stanford Journal of International Law* 28 (1991), p. 103; P. Cullet, "Definition of an environmental right in a human rights context," *Netherlands Quarterly of Human Rights* 13/1 (1995), pp. 25–40; United Nations Paris Agreement on Climate Change (2015), preambular para. 11.
16. *Juliana v. United States*, No. 6:15-CV-01517-TC, 2016 WL 6661146 (D. Or. Nov. 10, 2016); MacDonald (see note 8); Committee on the Rights of the Child, *Report of the 2016 general day of discussion: Children's rights and the environment*. Available at [http://www.ohchr.org/\\_layouts/15/WopiFrame.aspx?sourcedoc=/Documents/HRBodies/CRC/Discussions/2016/DGDoutcomereport-May2017.docx&action=default&DefaultItemOpen=1](http://www.ohchr.org/_layouts/15/WopiFrame.aspx?sourcedoc=/Documents/HRBodies/CRC/Discussions/2016/DGDoutcomereport-May2017.docx&action=default&DefaultItemOpen=1).
17. H. S. Cho and O. W. Pedersen, "Environmental rights and future generations," in M. Tushnet, T. Fleiner, and C. Saunders (eds), *Routledge handbook of constitutional law, 1st edition* (London: Routledge, 2013), pp. 401–412.
18. T. Hayward, *Constitutional environmental rights* (Oxford: Oxford University Press, 2005).
19. M. Thorme, "Establishing environment as a human right," *Denver Journal of International Law and Policy* 19 (1990), p. 301.
20. United Nations Office of the High Commissioner, *Special Rapporteur on human rights and the environment*. Available at <https://www.ohchr.org/en/Issues/environment/SREnvironment/Pages/SREnvironmentIndex.aspx>.
21. M. Amérigo, J. I. Aragonés, B. de Frutos, et al., "Underlying dimensions of ecocentric and anthropocentric environmental beliefs," *Spanish Journal of Psychology* 10/1 (2007), pp. 97–103.
22. Convention on the Rights of the Child, G.A. Res. 44/25 (1989).
23. MacDonald (see note 9).
24. P. H. Kahn and S. R. Kellert (eds), *Children and nature: Psychological, sociocultural, and evolutionary investigations* (Cambridge, MA: MIT Press, 2002).
25. F. Z. Ksentini, *Human rights and the environment: Final report*, UN Doc. E.CN.4/Sub.2/1994/9 (1994).
26. S. E. Brice, "Convention on the rights of the child: Using a human rights instrument to protect against environmental threats," *Georgetown International Environmental Law Review* 7 (1995), pp. 587–611.
27. United Nations Framework Convention on Climate Change, *Historic Paris Agreement on climate change: 195 nations set path to keep temperature rise well below 2 degrees Celsius*. Available at <https://unfccc.int/news/finale-cop21>; J. Ellsmore, "Business and youth unite to unleash the sustainable development goals," *Forbes* (June 6, 2018). Available at <https://www.forbes.com/sites/jamesellsmoor/2018/06/06/business-and-youth-unite-to-unleash-the-sustainable-development-goals/#58a56de6399b>.
28. D. Pearce, H. Apsimon, and E. Ozdemiroglu (eds), *Acid*

- rain in Europe: Counting the cost* (London: Routledge, 2014).
29. H. M. Osofsky, "Learning from environmental justice: A new model for international environmental rights," *Stanford Environmental Law Journal* 24 (2005), p. 71.
  30. Convention on Environmental Impact Assessment in a Transboundary Context (1991).
  31. B. Hayward, *Children, citizenship and environment: Nurturing a democratic imagination in a changing world* (London: Routledge, 2012).
  32. J. Dyson, *Working childhoods: Youth, agency and the environment in India* (Cambridge: Cambridge University Press, 2014).
  33. B. Hayward (see note 34).
  34. J. H. Lee, D. Scott, and M. F. Floyd, "Structural inequalities in outdoor recreation participation: A multiple hierarchy stratification perspective," *Journal of Leisure Research* 33/4 (2001), pp. 427–449; K. A. Shores, D. Scott, and M. F. Floyd, "Constraints to outdoor recreation: A multiple hierarchy stratification perspective," *Leisure Sciences* 29/3 (2007), pp. 227–246; J. Byrne, J. Wolch, and J. Zhang, "Planning for environmental justice in an urban national park," *Journal of Environmental Planning and Management* 52/3 (1009), pp. 365–392.
  35. C. Walker, "Environment and children's everyday lives in India and England: Exploring children's situated perspectives on global-local environmental concerns," in A. T. D. Imoh, M. F. C. Bourdillon, and S. Meichsner (eds), *Global childhood beyond the North-South divide* (Switzerland: Springer, 2019).
  36. K. T. Ferguson, R. C. Cassells, J. W. MacAllister, and G. W. Evans, "The physical environment and child development: An international review" *International Journal of Psychology* 48/4 (2013), pp. 437–468.
  37. A.-C. Prévot-Julliard, R. Julliard, and S. Clayton, "Historical evidence for nature disconnection in a 70-year time series of Disney animated films," *Public Understanding of Science* 24/6 (2015), pp. 672–680.
  38. R. Louv, *Last child in the woods: Saving our children from nature-deficit disorder* (Chapel Hill: Algonquin Books, 2005).
  39. Ibid.
  40. A. Goodman, R. Joyce, and J.P. Smith, "The long shadow cast by childhood physical and mental problems on adult life," *Proceedings of the National Academy of Sciences* 108/15 (2011), pp. 6032–6037.
  41. Kahn and Kellert (see note 24).
  42. S. J. Hunt, *The life course: A sociological introduction* (London: Palgrave Macmillan, 2016).
  43. N. M. Wells and K. S. Lekies, "Nature and the life course: Pathways from childhood nature experiences to adult environmentalism," *Children Youth and Environments* 16/1 (2006), pp. 1–24.
  44. A. Nairn, B. Duffy, O. Sweet, et al., *Children's well-being in UK, Sweden and Spain: The role of inequality and materialism* (Ipsos MORI Social Research Institute, 2011).
  45. Z. Barlow, "Confluence of streams: An introduction to the ground-breaking work of the Center for Ecoliteracy," *Resurgence* (2004), pp. 6–9.
  46. National Trust, *Natural childhood report* (2012).
  47. Ibid.; Convention on the Rights of the Child, G.A. Res. 44/25 (1989), art. 24.
  48. A. C. K. Lee and R. Maheswaran, "The health benefits of urban green spaces: A review of the evidence," *Journal of Public Health* 33/2 (2011), pp. 212–222; V. Derr and K. Lance, "Biophilic Boulder: Children's environments that foster connections to nature," *Children, Youth and Environments* 22/2 (2012), pp. 112–143.
  49. W. Bird, *Natural fit: Can green space and biodiversity increase levels of physical activity?* (Royal Society for the Protection of Birds, 2004).
  50. C. H. Hillman, K. I. Erickson, and A. F. Kramer, "Be smart, exercise your heart: Exercise effects on brain and cognition," *Nature Reviews Neuroscience* 9/1 (2008), p. 58.
  51. Walker (see note 35).
  52. A. Sigman, *Agricultural literacy: Giving concrete children food for thought* (2007). Available at <https://slidex.tips/download/agricultural-literacy>.
  53. National Trust (see note 46).
  54. Ibid.
  55. G. De Fraja, T. Oliveira, and L. Zanchi, "Must try harder: Evaluating the role of effort in educational attainment," *Review of Economics and Statistics* 92/3 (2010), pp. 577–597.
  56. Ibid.
  57. L. Legault and L.G. Pelletier, "Impact of an environmental education program on students' and parents' attitudes, motivation, and behaviours," *Canadian Journal of Behavioural Science* 32/4 (2000), p. 243.
  58. Intergovernmental Panel on Climate Change, *Managing the risks of extreme events and disasters to advance climate change adaptation* (2018).
  59. F. M. Burkle Jr., G. Martone, and P. G. Greenough, "The changing face of humanitarian crises," *Brown Journal of World Affairs* 20 (2013), p. 19.
  60. International Save the Children Alliance, *In the face of disaster: Children and climate change* (London: International Save the Children Alliance, 2008).
  61. D. Selby and F. Kagawa, *Disaster risk reduction in school curricula: Case studies from thirty countries* (Paris: UNESCO and UNICEF, 2012).
  62. V. Marchezini, R. Trajber, D. Olivato, et al., "Participatory early warning systems: Youth, citizen science, and intergenerational dialogues on disaster risk reduction in Brazil," *International Journal of Disaster Risk Science* 8/4 (2017), pp. 390–401.
  63. P. McDiarmind, *In the face of disaster: Children and climate change* (London: International Save the Children Alliance, 2008).
  64. Ibid.; Asian Management Development Institute.



Available at: <http://weadapt.org/organisation/amdi>.

65. A. Boyle, "Human rights or environmental rights? A reassessment," *Fordham Environmental Law Review* (2007), pp. 471-511.

66. L. Peek, "Children and disasters: Understanding vulnerability, developing capacities, and promoting resilience—An introduction," *Children, Youth and Environments* 18/1 (2008), pp. 1-29.

67. L. Cumiskey, T. Hoang, S. Suzuki, et al., "Youth participation at the third UN world conference on disaster risk reduction," *International Journal of Disaster Risk Science* 6/2 (2015), pp. 150-163.

68. R. Haines-Young and M. Potschin, "The links between biodiversity, ecosystem services and human well-being," *Ecosystem Ecology: A New synthesis* 1 (2010), pp. 110-139.

69. H. Tallis, P. Kareiva, M. Marvier, and A. Chang, "An ecosystem services framework to support both practical conservation and economic development," *Proceedings of the National Academy of Sciences* 105/28 (2008), pp. 9457-9462.

70. G. C. Daily, S. Polasky, J. Goldstein, et al., "Ecosystem services in decision making: Time to deliver," *Frontiers in Ecology and the Environment* 7/1 (2009), pp. 21-28.

71. Waipa Foundation. Available at <http://www.waipafoundation.org/about>.

72. Tallis et al. (see note 69).

73. A. Oposa, Jr., "Intergenerational responsibility in the Philippine context as a judicial argument for public action on deforestation," Fourth International Conference on Environmental Compliance and Enforcement, Makati, Philippine Ecological Network (2000).

74. Our Children's Trust, *Active state legal actions: Oregon*. Available at <https://www.ourchildrenstrust.org/oregon>.

75. D. Walden, N. Hall, and K. Hawrylyshyn, *Global warning: Children's right to be heard in global climate change negotiations* (London: Plan UK, 2009).

76. United Nations Framework Convention on Climate Change (see note 27).

77. J. Ellsmore, "Business and youth unite to unleash the sustainable development goals," *Forbes* (June 6, 2018). Available at <https://www.forbes.com/sites/jamesellsmoor/2018/06/06/business-and-youth-unite-to-unleash-the-sustainable-development-goals/#58a56de6399b>.

78. A. Davies and F. Gathorne-Hardy, *Making connections: Community involvement in environmental initiatives* (Cambridge: CIES, 1997).

79. J. Blake, "Overcoming the 'value-action gap' in environmental policy: Tensions between national policy and local experience," *Local Environment* 4/3 (1999), pp. 257-278.

80. M. Brown and J. McCormack, "Placing children on the political agenda: New Zealand's agenda for children," in J. Goddard, S. McNamee, and A. James (eds), *The politics of childhood* (London: Palgrave Macmillan, 2005), pp. 185-207; L. Jamieson and W. Mukoma, "Dikwankwetla—Children in action: Children's participation in the law reform process

in South Africa," in B. Percy-Smith and N. Thomas (eds), *A handbook of children and young people's participation* (London: Routledge, 2009), pp. 95-104; K. Pells, "'No one ever listens to us': Challenging obstacles to the participation of children and young people in Rwanda," in B. Percy-Smith and N. Thomas (eds), *A handbook of children and young people's participation: Perspectives from theory and practice* (London: Routledge, 2009), pp. 196-203.

81. A. Bajpai, *Child rights in India: Law, policy, and practice* (Oxford: Oxford University Press, 2018).

82. J. Wall, "Can democracy represent children? Toward a politics of difference," *Childhood* 19/1 (2012), pp. 86-100.

83. *Ibid.*

84. C. N. Radavoi and Y. Bian, "Enhancing the accountability of transnational corporations: The case for 'decoupling' environmental issues," *Environmental Law Review* 16/3 (2014), pp. 168-182.

85. K. Murphy, "Enforcing tax compliance: To punish or persuade?," *Economic Analysis and Policy* 38/1 (2008), pp. 113-135.

86. Funds for NGOs, *Three grantmaking foundations that fund children's projects around the world*. Available at <http://www.fundsforngos.org/article-contributions/grant-making-foundations-fund-childrens-projects-world>.



# Asylum Medicine: Standard and Best Practices

HOPE FERDOWSIAN, KATHERINE MCKENZIE, AND AMY ZEIDAN

## Abstract

Due to global events in recent years, applications for political asylum have increased, although the number of people granted asylum in the United States and elsewhere has declined. Physicians and other health care professionals can play a crucial role in the evaluation of individuals seeking asylum, since appropriately documented objective clinical evidence of torture and other forms of persecution can increase the likelihood that survivors of human rights abuses obtain asylum. Many clinicians have the requisite expertise and skills needed to conduct forensic asylum evaluations. However, despite growing interest in this area, the demand for medical and psychiatric forensic evaluations exceeds the number of clinicians who are prepared to conduct asylum evaluations. In an effort to increase the number of qualified clinicians interested and involved in medical and psychiatric evaluations of asylum seekers, this article offers a summary of standard and best practices in the area, including recommended qualifications and competencies relevant to the practice of forensic asylum evaluations, guidance on effective approaches to the medical and psychiatric evaluation of asylum seekers, and recommendations related to medicolegal documentation and testimony. We also highlight gaps in evidence regarding best practices.

---

HOPE FERDOWSIAN, MD, MPH, FACP, FACPM, is an associate professor of medicine in the Department of Internal Medicine at the University of New Mexico School of Medicine, Albuquerque, NM, USA.

KATHERINE C. MCKENZIE, MD, FACP, is director of the Yale Center for Asylum Medicine and an assistant professor of medicine in the Department of Internal Medicine at the Yale School of Medicine, New Haven, CT, USA.

AMY ZEIDAN, MD, is a clinical instructor and ultrasound fellow in the Department of Emergency Medicine at the University of Kentucky College of Medicine, Lexington, KY, USA.

Please address correspondence to Hope Ferdowsian. Email: [hferdowsian@salud.unm.edu](mailto:hferdowsian@salud.unm.edu).

Competing interests: Hope Ferdowsian is a medical expert and volunteer for Physicians for Human Rights and HealthRight International. She has been compensated in the past as a lead trainer in asylum medicine training sessions. Her book, *Phoenix Zones: Where Strength Is Born and Resilience Lives*, addresses human rights abuses, including torture. Katherine McKenzie is a volunteer for Physicians for Human Rights and has been compensated in the past as a lead trainer in asylum training sessions. She volunteers for nonprofit organizations such as American Friends Service Committee, Connecticut Institute for Immigrants and Refugees, Integrated Refugee and Immigrant Services, New Haven Legal Assistance Association, and HealthRight International. When traveling to detention facilities, she is compensated for her travel expenses. She was paid to speak at Stony Brook University Grand Rounds on a subject relevant to asylum medicine. Amy Zeidan is a volunteer for Physicians for Human Rights. All three authors openly advocate for human rights.

Copyright © 2019 Ferdowsian, McKenzie, and Zeidan. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted noncommercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

## Introduction

Worldwide, conflict, violence, and persecution have driven internal and external displacement to a higher level each year for five consecutive years. As a result, the global number of refugees and asylum seekers has increased significantly, fueling human rights and public health concerns. Individuals seeking asylum commonly assert a history or risk of violent persecution, as well as corresponding physical and mental health challenges. If forced to return to their country of origin, asylum seekers commonly face the risk of severe injury or death.

By the end of 2017, the number of people seeking asylum worldwide rose to more than three million, while the number of countries hosting large numbers of displaced persons has remained relatively small.<sup>1</sup> In the United States, applications for asylum have increased, although the number of people granted asylum has declined in recent years.<sup>2</sup>

Asylum law emerged from human rights treaties created after the Second World War, including the Universal Declaration of Human Rights, the United Nations Convention relating to the Status of Refugees, and the US Refugee Act.<sup>3</sup> In order to qualify for asylum, applicants need to show that they have suffered or will likely suffer persecution in their country of origin based on their political opinion, race, religion, nationality, or membership in a certain social group. Torture and other forms of abuse are considered protected forms of persecution under US law. Physicians therefore have an important role to play in the evaluation of individuals seeking asylum. Appropriately documented objective clinical evidence of torture or ill treatment can increase the likelihood that survivors of human rights abuses obtain asylum. One study showed that 89% of asylum seekers who had undergone a clinical evaluation were granted asylum, in contrast with a national average of 37.5% of asylum seekers at the time.<sup>4</sup>

Presently, the demand for forensic asylum evaluations in the United States exceeds the number of clinicians prepared to conduct them.<sup>5</sup> This may be particularly true in certain areas of the country, especially non-urban areas, and in cases requiring mental health assessments. Despite the growing

need for qualified experts, there is limited professional, practical, and ethical guidance for interested medical professionals. Similarly, despite growing interest in and satisfaction with this area of medicine, there is a paucity of published best practices relevant to the evaluation of asylum seekers and the training of qualified medical professionals.<sup>6</sup> The Istanbul Protocol, published in 1999, was the first set of international standards for the documentation of torture and its consequences.<sup>7</sup> Since then, some nongovernmental organizations have provided a small number of reference materials to trainees, and scholars have published papers and books on the role of physicians and other health care professionals in asylum evaluations, the purpose of and basic approach to an asylum evaluation, and the health needs of asylum seekers.<sup>8</sup> Although all of these resources offer important information, they are perhaps too lengthy, impractical, and nonspecific for interested health care professionals with busy schedules and multiple clinical and nonclinical demands.

In an effort to increase the number of qualified clinicians interested and involved in asylum evaluations, we offer a brief summary of standard and best practices specific to the forensic evaluation of asylum seekers. Our recommendations are informed by published standards, where available, as well as legal and ethical considerations. Published standards for the forensic evaluation of asylum seekers generally reflect instruction provided by organizations such as Physicians for Human Rights and HealthRight International (formerly Doctors of the World-USA), as well as the 1999 Istanbul Protocol. However, other forms of forensic medicine instruction may also inform best practices. This article aims to provide a summary of the most widely published practices in forensic evaluations specific to asylum seekers and to encourage further discussion about basic standards and best practices in this area.

Sometimes referred to as “asylum medicine,” the objective forensic evaluation of asylum seekers offers physicians and other clinicians an opportunity to use their knowledge and skills to serve a particularly vulnerable population. Although health care professionals can support asylum seek-

ers and refugees in myriad other ways, this article is limited to the role of physicians and other clinicians in the forensic evaluation of asylum seekers.

## Recommended qualifications and competencies for forensic asylum evaluations

### *Qualifications and expectations*

The purpose of an asylum evaluation is to obtain facts pertinent to the asylum seeker's history of torture, ill treatment, or persecution; perform a focused exam to document physical and psychological evidence of trauma; and establish the level of consistency between the person's history and exam findings. Physicians, mental health professionals, and other clinicians already possess many of the basic skills necessary to conduct asylum evaluations, including empathic medical interviewing skills, the physical and psychological assessment of trauma sequelae, and medical documentation. With further study, training, or mentorship, such knowledge and skills may be honed toward the forensic evaluation of asylum seekers. Many clinicians have the requisite capacities to develop experience and expertise in this area.

Clinicians who conduct asylum evaluations are not expected to provide treatment. Instead, they are expected to summarize their encounter with the asylum seeker and their findings in the form of a medicolegal report, which may then be used by the asylum seeker's attorney.<sup>9</sup> A medicolegal report typically requires the responsible clinician to present findings that support or refute a history of torture or ill treatment, as well as an assessment on the risks involved in returning the applicant to their country of origin and on other risks related to the asylum seeker's health conditions.<sup>10</sup>

Although there is no national licensure available or required for clinicians who perform asylum evaluations, some organizations provide certification of training.<sup>11</sup> No published studies have evaluated the merits of certification of training or prior experience in determining asylum outcomes, which are primarily distinguished by legal jurisdiction.<sup>12</sup> The Federal Rules of Evidence,

a set of rules that govern the introduction of evidence in US federal trial courts, provide standards for the admission of expert evidence and refer to the "knowledge, skill, experience, training, or education" of the individual performing the evaluation. Knowledge, skill, experience, training, and education can be demonstrated by the inclusion of a curriculum vitae or a statement within the medicolegal report.<sup>13</sup>

### *General competencies*

To be useful and effective as asylum evaluators, physicians and other qualified professionals may need to expand their traditional roles. At a minimum, clinicians who perform asylum evaluations should be able to demonstrate the following competencies.<sup>14</sup>

1. Familiarity with asylum law and the role of clinicians in evaluating asylum seekers
2. Knowledge of medical and mental health consequences of torture and ill treatment (Table 1)
3. An objective and professional approach that includes respect for privacy and confidentiality, informed consent, appropriate language interpretation services, and attention to trauma-informed care
4. Relevant history-taking and interview techniques and physical examination skills
5. Familiarity with standardized language for describing the diagnostic probability or consistency of medical and mental health findings, often guided by the Istanbul Protocol (Table 2)
6. Medicolegal documentation as it pertains to the clinical assessment of asylum seekers (Table 3)
7. Effective and responsive interpersonal and communication skills that extend to legal professionals and referring agencies
8. Ongoing personal and professional development, including continuing education and attention to the potential for vicarious trauma

More specific competencies may be required of those who perform specialized clinical assessments or who serve as mentors or trainers. Ideally, train-

ing programs should be conducted by experienced asylum evaluators who are attentive to key competencies and offer attendees the potential for ongoing mentorship and professional development.

## Preparation for and performance of asylum evaluations

### *Preparation*

Clinicians new to asylum evaluations can typically connect with asylum seekers in three different ways. First, some nonprofit organizations connect clinicians interested in performing asylum evaluations with legal professionals and their clients.<sup>15</sup> In addition, a number of asylum clinics organized by medical students connect clinicians with training opportunities, mentorship, and scheduled asylum evaluations (Table 4).<sup>16</sup> Finally, for those who practice where formal processes do not exist, opportunities may be identified through local resettlement and

legal agencies that work with immigrants.

Communication with an asylum seeker's attorney in advance of the clinical evaluation is paramount. This discussion should include the purported legal rationale for asylum, the type of clinical evaluation indicated, and any concerns of the legal team. In advance of the visit, the clinician should review materials provided by the attorney, including the asylum seeker's statement and any relevant medical records. Clinicians can also consult the literature about findings related to specific types of torture or country conditions.

Finally, it is important to arrange for appropriate interpretation services, with attention to dialect as well as cultural, gender, and other individual considerations. Professional medical interpretation is preferred and can be arranged by the asylum seeker's attorney. Although in-person interpretation services are optimal, some situations may require the use of a professional telephone interpretation service.

TABLE 1. Common medical and psychiatric findings after torture or ill treatment

Organ system or discipline	Specific injuries or ailments	Description	Notes
Dermatologic*	Laceration	Tear in skin	<ul style="list-style-type: none"> <li>Typically results from blunt trauma</li> <li>Shape may reflect the design and force of the instrument, including beating with a baton or similar object, whipping with a belt or similar object, a human bite, or a gunshot wound</li> </ul>
	Incision	Precise tear in skin	<ul style="list-style-type: none"> <li>Typically produced from sharp objects</li> <li>Causative instruments may include knives, razorblades, scalpels, or glass</li> </ul>
	Abrasion	Superficial injury to skin	<ul style="list-style-type: none"> <li>Typically caused by friction</li> <li>Careful examination may allow identification of the instrument and direction of force</li> </ul>
	Burn	Injury caused by exposure to heat, electricity, or acid	<ul style="list-style-type: none"> <li>Typically caused by electrical, thermal, or chemical energy</li> <li>Scars vary depending on the source and duration of burn, personal characteristics, and course of healing</li> <li>Cigarette burns and branding commonly leave characteristic scars</li> <li>Electrical burns are less likely to leave distinct scars</li> </ul>
Neurologic	Traumatic brain injury	Disruption of the normal function of the brain	<ul style="list-style-type: none"> <li>May result from blunt trauma, a jolt, penetrating head injury, or suffocation, including near drowning (e.g., waterboarding) and strangulation</li> <li>Neurological examination, including neurocognitive assessment, is essential; such assessment may include the use of screening tools such as the Montreal Cognitive Assessment test</li> <li>Symptoms may overlap with those of mental disorders</li> </ul>
	Post-concussion syndrome	Concussive symptoms after trauma	<ul style="list-style-type: none"> <li>Symptoms may include a history of headaches, sleep impairment, or impaired memory or concentration</li> <li>Symptoms may overlap with those of mental disorders</li> </ul>
	Peripheral neuropathy	Injury to the peripheral nerves	<ul style="list-style-type: none"> <li>May result from blunt trauma, suspension, or burns</li> <li>Early sequelae may include diminished mobility, pain, or numbness</li> <li>Later sequelae may include asymmetric weakness or paresthesias</li> </ul>

*Approach to the evaluation: Informed consent and interview considerations*

As with all clinical interactions, it is essential to set expectations and obtain informed consent. Care should be taken to explain to the asylum seeker that the health care professional’s role is as a forensic eval-

uator rather than as a treating clinician. Clinicians should articulate the limitations of confidentiality, including that relevant findings will be described in a report that may be viewed by individuals involved in the legal process. If there are components of the history or exam that the asylum seeker is uncom-

TABLE 1. *continued*

Organ system or discipline	Specific injuries or ailments	Description	Notes
Orthopedic	Arthralgias	Pain or discomfort involving the joints or spine	<ul style="list-style-type: none"> <li>• May result from beatings, forced positioning, confinement, weight-bearing activities, or forced crawling</li> <li>• Neck and back pain are commonly reported</li> </ul>
	Myalgias	Pain or discomfort involving the muscles	<ul style="list-style-type: none"> <li>• May result from beatings, forced positioning, confinement, weight-bearing activities, or nutritional deprivation</li> <li>• History may reveal evidence of myoglobinuria</li> </ul>
	Fractures	Interruption of normal bone tissue	<ul style="list-style-type: none"> <li>• May be displaced or nondisplaced</li> <li>• Lack of access to medical treatment may result in abnormal healing and unusual physical exam findings</li> </ul>
	Falanga	Beating of the soles of the feet	<ul style="list-style-type: none"> <li>• Early symptoms may include bruising, swelling, or pain</li> <li>• Later symptoms may include pain and problems with ambulation</li> <li>• Examination findings may reveal an awkward gait or deformities of the feet</li> </ul>
Otolaryngology	Dental	Trauma involving dentition	<ul style="list-style-type: none"> <li>• May include intrusion, displacement, or fracture</li> </ul>
	Telefono	Blunt trauma to the ears	<ul style="list-style-type: none"> <li>• Early symptoms may include pain, bleeding, tinnitus, or hearing loss</li> <li>• Late symptoms may include rupture or scarring of the tympanic membrane, tinnitus, or hearing loss</li> </ul>
Genitourinary and gynecological	Sexual violence	Any form of nonconsensual interaction with the sexual organs, including the urogenital region, anal region, and breast tissue; may include female genital mutilation/cutting	<ul style="list-style-type: none"> <li>• Physical evidence of sexual violence is difficult to obtain, particularly as time elapses; psychological evidence is more common after sexual violence</li> <li>• Chronic sequelae of sexual violence varies and may include sexual dysfunction, sexually transmitted infections, urinary tract infections, chronic pain syndromes, pregnancy and potential complications of pregnancy, or psychiatric findings, as indicated below</li> </ul>
Psychiatric	Mental illness	Mental health issues that may or may not meet diagnostic criteria for designated psychiatric disorders	<ul style="list-style-type: none"> <li>• Individuals may meet diagnostic criteria for mental disorders, including posttraumatic stress disorder, major depression, generalized anxiety disorder, adjustment disorders, somatoform disorders, substance use disorders, obsessive-compulsive disorders, and eating disorders, among others</li> <li>• General symptoms are also possible, including fear; confusion; anxiety; anger; sadness; social withdrawal or dysfunction; problems with self-esteem; sleep disturbances; impairments in cognition, including deficits in memory, attention, language, and learning; chronic pain; sexual dysfunction, including dyspareunia and decreased sexual interest; and global dysfunction</li> </ul>

\*Scar appearance will depend on several factors, including force and velocity of trauma, the characteristics of the object and surface subject to trauma, skin plasticity and pigmentation, comorbid medical problems, and access to medical treatment before, during, and after torture or ill treatment.

Sources: Office of the United Nations High Commissioner for Human Rights, Istanbul protocol: Manual on the effective investigation and documentation of torture and other cruel, inhuman or degrading treatment or punishment, Professional Training Series No. 8/Rev. 1 (2004); Physicians for Human Rights, Examining asylum seekers: A clinician’s guide to physical and psychological evaluations of torture and ill-treatment (Cambridge, MA: Physicians for Human Rights, 2012); HealthRight International, Training manual for physicians and mental health professionals (New York: HealthRight International, 2010); V. Iacopino, “Medical evaluations of asylum seekers,” *AMA Journal of Ethics*, September 2004; D. Forrest, “Examination for the late physical after effects of torture,” *Journal of Clinical Forensic Medicine* 6 (1999), pp. 4–13; A. Moreno and M. A. Grodin, “Torture and its neurological sequelae,” *Spinal Cord* 40 (2002), pp. 213–223; L. Danielsen and O. V. Rasmussen, “Dermatological findings after alleged torture,” *Torture* 16 (2006), pp. 108–127.



TABLE 2. Degrees of consistency

Not consistent	The lesion could not have been caused by the trauma described
Consistent with	The lesion could have been caused by the trauma described, but it is nonspecific and there are many other possible causes
Highly consistent	The lesion could have been caused by the trauma described, and there are few other possible causes
Typical of	This is an appearance that is usually found with this type of trauma, but there are other possible causes
Diagnostic of	This appearance could not have been caused in any way other than that described

Source: Reprinted with permission from K. C. McKenzie, J. Bauer, and P. P. Reynolds, "Asylum seekers in a time of record forced global displacement: The role of physicians," *Journal of General Internal Medicine* 34 (2019), pp. 137–143. Adapted from Istanbul protocol: Manual on the effective investigation and documentation of torture and other cruel, inhuman or degrading treatment or punishment, UNHCR Professional Training Series No. 8/Rev. 1 (2004).

TABLE 3. Medicolegal documentation: General guidance\*

General segment	Examples of details for inclusion
Evaluator's professional background and qualifications	<ul style="list-style-type: none"> <li>Professional affiliation(s)</li> <li>Education and training history</li> <li>Any other relevant experience, training, or expertise</li> </ul>
Description of evaluation	<ul style="list-style-type: none"> <li>Referral information regarding the asylum seeker</li> <li>Informed consent documentation</li> <li>Individual's name, date of birth, age, location of birth, gender, and any other identifying characteristics relevant to the evaluation</li> <li>Date, location, and duration of evaluation</li> <li>Use and description of interpretation services, if applicable</li> <li>Names and brief descriptors of any others present for the evaluation</li> <li>Materials or resources reviewed prior to the evaluation</li> </ul>
Relevant history of asylum seeker	<ul style="list-style-type: none"> <li>Relevant past medical or surgical history, family and social history, or prior trauma, as well as any relevant treatment</li> </ul>
Reported account of torture, ill treatment, or other form(s) of persecution	<ul style="list-style-type: none"> <li>Circumstances of arrest, detention, torture, or ill treatment</li> <li>Physical or mental symptoms</li> <li>Access to medical or psychiatric care and details of care, if relevant</li> </ul>
Physical examination, if indicated	<ul style="list-style-type: none"> <li>General appearance</li> <li>Itemized findings related to torture or ill treatment</li> <li>Any significant findings unrelated to torture or ill treatment</li> <li>Inclusion of cognitive assessment or other screening or diagnostic tests, if indicated</li> <li>Relevant behavioral observations during the evaluation</li> </ul>
Psychological or psychiatric examination, if indicated	<ul style="list-style-type: none"> <li>Methods of assessment (e.g., screening or diagnostic tools)</li> <li>Findings and consistency with diagnostic criteria, if indicated</li> </ul>
Any other findings, if indicated	<ul style="list-style-type: none"> <li>Laboratory or other diagnostic results**</li> </ul>
Summary and interpretation of findings and recommendations	<ul style="list-style-type: none"> <li>Assessment and summary of the degree of consistency between history, exam findings, and other available information</li> <li>Assessment and summary of the degree of consistency between comprehensive findings, history of torture or ill treatment, and anticipated clinical sequelae</li> <li>Any recommendations for further assessment, treatment, or care</li> </ul>

\* The report format can vary depending on the evaluator's preferences, type of evaluation performed, and other factors.

\*\* Often, resources are limited, and laboratory and radiological examination are unnecessary.

Sources: Office of the United Nations High Commissioner for Human Rights, Istanbul protocol: Manual on the effective investigation and documentation of torture and other cruel, inhuman or degrading treatment or punishment, Professional Training Series No. 8/Rev. 1 (2004); Physicians for Human Rights, *Examining asylum seekers: A clinician's guide to physical and psychological evaluations of torture and ill-treatment* (Cambridge, MA: Physicians for Human Rights, 2012); HealthRight International, *Training manual for physicians and mental health professionals* (New York: HealthRight International, 2010); E. Scruggs, T. C. Guetterman, A. C. Meyer, et al., "An absolutely necessary piece: A qualitative study of legal perspectives on medical affidavits in the asylum process," *Journal of Forensic and Legal Medicine* 44 (2016), pp. 72–78; A. Pitman, "Medicolegal reports in asylum applications: A framework for addressing the practical and ethical challenges," *Journal of the Royal Society of Medicine* 103 (2010), pp. 93–97; M. Peel and V. Iacopino, *The medical documentation of torture* (San Francisco: Greenwich Medical Media, 2002).

fortable exposing in a written report, these items should be clarified during the interview.

An asylum evaluation can be lengthy and invasive for individuals as they relive traumatic experiences from their past. A number of interview techniques can create a safe environment, including nonthreatening questions, active listening, and attention to body language.<sup>17</sup> The interview should be guided by the principles of objectivity and trauma-informed care. Open-ended questions are preferred, with the use of more specific questioning to clarify details.

### *Physical evaluation*

Asylum seekers with physical evidence of torture or ill treatment may display scars, injuries, or ongoing physical ailments (Table 1). Responses to torture and ill treatment vary depending on one's personal characteristics, medical history, the type and severity of torture employed, methods of restraint, access to treatment, and other factors.<sup>18</sup> A comprehensive exam from head to toe, with a focused assessment of skin, is useful to avoid missing evidence of trauma.<sup>19</sup> Clinicians should also note significant findings unrelated to torture or ill treatment.

Several resources are integral to a physical evaluation, including a ruler, camera, anatomical diagrams, and diagnostic materials required for systems-based examination. When reporting exam findings, clinicians should document the relationship between observed physical characteristics and the mechanism of trauma described, as well as a clinical assessment regarding the level of consistency or diagnostic probability of the trauma described (Table 2).<sup>20</sup> Clinicians should attempt to obtain explanations for each scar, which they should measure, describe, and record in text and a diagram, if possible. The site, size, shape, color, borders, and surrounding area of each injury should also be documented.<sup>21</sup>

Some asylum seekers may be hesitant to disclose injuries or scars, or they may have significant memory deficits that make exact mechanisms of injury difficult to recall. Explanations for recall deficits include loss of consciousness during torture, significant emotional disturbances, and

traumatic brain injury.<sup>22</sup> Additionally, the frequency and severity of injury may be so extreme that it becomes difficult to differentiate each scar by an exact etiology. In these instances, it is important to document as many pertinent findings from the history and exam as possible.

### *Psychological or psychiatric evaluation*

Psychological findings constitute some of the most common chronic sequelae of torture. Most individuals who experience traumatic events suffer posttraumatic psychiatric symptoms and are at higher risk of developing mental illness (Table 1).<sup>23</sup> Therefore, a psychological evaluation of an asylum seeker should consist of a mental health history, past and present psychiatric symptoms, an assessment of global functioning, and screening for and diagnosis of mental illness if indicated. Due to the increasing demand for psychological evaluations, many non-psychiatrists commonly perform psychological evaluations of asylum seekers as they would of patients in their normal practice.<sup>24</sup> Nonetheless, as with any clinical mental health evaluation, the approach differs from that of a physical evaluation and commonly involves an extended interview supported by specific techniques and tools.

There are several useful screening and diagnostic tools that can be utilized during the course of a mental health evaluation. Although not specifically designed for asylum seekers, screening tools that can assist with psychological evaluations include the Primary Care Posttraumatic Stress Disorder 5, the Patient Health Questionnaire 9 (for depression), and the Posttraumatic Stress Disorder Symptom Scale 5.<sup>25</sup> These tools can be used to screen for mental disorders, whereas the Diagnostic and Statistical Manual of Mental Disorders can be used for diagnostic purposes.<sup>26</sup> Additionally, screening tools for assessing cognitive impairment, such as the Montreal Cognitive Assessment test, may be useful for identifying potential contributors to abnormal mood or cognition.<sup>27</sup>

Additionally, within the fields of forensic psychiatry and forensic psychology, there are specific tools and best practices that appropriately trained

professionals can reference and use. However, no published studies have compared different methods of psychiatric or psychological evaluation in determining asylum outcomes.

Regardless of the methods or tools used by evaluators, it is important to remember that an individual's response to torture and other forms of trauma may be influenced by their cultural background and individual characteristics. Factors that promote resilience and healing, including individual and environmental contributors, may also influence how asylum seekers reflect a history of trauma.<sup>28</sup> Access to treatment can also affect healing and resilience and should be taken into account during any psychological evaluation. Further,

language differences can confound how an asylum seeker interprets the clinician's screening and diagnostic questions, as well as how the clinician interprets the asylum applicant's responses.

### Medicolegal documentation and testimony

#### *Medicolegal documentation*

Typically, three primary domains are covered in a medicolegal report: background information, examination findings and supplementary evidence, and conclusions (Table 3). Findings and conclusions are generally reported in a manner that is specific to the type of evaluation performed. For example, if an evaluation is limited to a physical examination,

TABLE 4. Nongovernmental organizations and academic medical centers offering asylum medicine training or services\*

Albert Einstein College of Medicine
Brown Human Rights Asylum Clinic
Capital District Asylum Collaborative (Albany, NY)
Columbia Human Rights Initiative Asylum Clinic
CUNY/Sophie Davis
Dartmouth
Georgetown School of Medicine Asylum Program
Harvard Student Human Rights Collaborative
HealthRight International**
Human Rights Clinic of Miami
Human Rights Initiative at the University of Buffalo
Mount Sinai Human Rights Program
New York Medical College Center for Human Rights
Philadelphia Human Rights Clinic
Physicians for Human Rights**
Touro Harlem Health Clinic
UConn School of Medicine
University of Michigan Asylum Collaborative
USC-Keck Human Rights Clinic
UTMB Galveston
Weill Cornell Center for Human Rights
Yale Center for Asylum Medicine

\* As of December 2018

\*\* Nongovernmental organizations

Sources: K. C. McKenzie, J. Bauer, and P. P. Reynolds, "Asylum seekers in a time of record forced global displacement: The role of physicians," *Journal of General Internal Medicine* 34 (2019), pp. 137-143; Physicians for Human Rights, *Focus areas: Persecution and asylum* (2018). Available at <https://phr.org/issues/asylum-and-persecution/#top>; HealthRight International, *Human Rights Clinic forensic evaluation services* (2018). Available at <https://healthright.org/forensic-evaluation-services>.

the medicolegal report should focus on pertinent exam findings, describing the consistency of each finding and summary of findings, as highlighted in the Istanbul Protocol (Table 2).<sup>29</sup> Medicolegal reports of psychological or psychiatric evaluations typically focus on the type of screening or diagnostic methods used, pertinent psychological findings, and conclusions. Within any medicolegal report, it is important to avoid equivocal, contradictory, confusing, and ambiguous language, as well as overly detailed accounts or extraneous information, which can be detrimental to an asylum applicant's case.<sup>30</sup> Although medical terminology is not necessarily discouraged, it should be accompanied by language that can be easily interpreted by an asylum officer or immigration judge.

As with other forms of documentation, clinicians should carefully review medicolegal reports for content, grammatical, and other errors. For novices, an experienced mentor can review the document. Once complete, the report should be shared with the asylum applicant's attorney and revised and finalized as appropriate. Some attorneys may request changes to or notarization of the document. Clinicians are not obliged to make edits based on attorneys' recommendations. Rather, clinicians should maintain an objective evaluation and documentation.

### *Forensic photography*

Photographs can be a powerful and useful part of a forensic evaluation, although the use of forensic photography has not necessarily been shown to influence judicial decisions.<sup>31</sup> The asylum applicant's consent for photography can be requested by the attorney prior to the evaluation, as well as at the time of the evaluation; careful attention should be paid to the potential for coercion or retraumatization. Although forensic reports are not anonymous, attempts should be made to maintain the individual's privacy, including by de-identifying the person in photographs. This can be done by avoiding photographs of the face or, if there are scars on the face, taking a partial photograph obscuring the person's eyes.

Photographs should be stored in a locked filing cabinet or on a computer that is password-protected

and encrypted at the level used for the protection of patient information. Photographs do not need to be individually labeled with the person's name; instead, they can be stored in a file with the individual's identifying information. Photographs can become part of the medicolegal report and shared with the person's attorney in a secure manner.

### *Testimony*

Typically, asylum evaluators are not asked to provide oral testimony in immigration court. If asked to do so, it is important to clarify with the attorney the reason for the testimony, whether it will be telephonic or in-court testimony, the date and time of the anticipated testimony, and whether a subpoena is involved. It may also be useful to discuss the case in further detail with the attorney and prepare for cross-examination.

### Conclusion

Currently, despite critical need and interest, relatively few health care professionals are adequately prepared to perform forensic asylum evaluations. Additionally, resource constraints limit the availability of training opportunities. In this article, we have aimed to provide an overview of standard practices in the forensic evaluation of asylum seekers so that clinicians may feel better prepared to participate in asylum evaluations. Clearly, there is a need for more work in this area, including rigorous discussion and an evidence-based evaluation of standard practices. Presently, the most important and consistent factors affecting the final outcome of an asylum case are jurisdiction and whether an attorney represents the asylum seeker.<sup>32</sup>

As clinicians who perform forensic asylum evaluations continue to develop and refine best practices, others who are interested in performing such evaluations can pursue training and mentorship opportunities offered by nonprofit organizations such as Physicians for Human Rights and HealthRight International, as well as continuing medical education, fellowships, and certification in specific areas of forensic medicine, psychology, and psychiatry.

We have not addressed a number of issues that deserve greater consideration, including the evaluation of minors, the evaluation of asylum seekers at detention centers, and the need to promote vicarious resilience among asylum medicine evaluators to reduce the risk for compassion fatigue.<sup>33</sup> As studies have shown, many individuals who work with torture or other trauma survivors benefit from the work, although there are also a number of personal and professional challenges that require attention.<sup>34</sup> Additionally, more robust discussion is needed on how clinicians can maintain objectivity and how they can continue to advocate for human rights protections without disqualifying themselves as forensic experts.<sup>35</sup>

In order to sustain and expand the practice of forensic asylum evaluations, systemic issues also need greater consideration. Network building and peer support are critical, as is institutional support. Most clinicians who perform asylum evaluations are not compensated, and academic centers and other health care systems frequently do not provide protected time for performing asylum evaluations or for teaching students and residents how to perform them.<sup>36</sup> Since many asylum seekers and their families live in communities served by these academic centers and health care systems, this issue merits further exploration. At a time when more global citizens are at risk for displacement, torture, and persecution, it is incumbent on the medical community to respond in kind.

## References

1. "Forced displacement above 68m in 2017, new global deal on refugees critical," *UNHCR USA Press Releases* (June 19, 2018). Available at <http://www.unhcr.org/en-us/news/press/2018/6/5b27c2434/forced-displacement-above-68m-2017-new-global-deal-refugees-critical.html>.
2. N. Mossaad and R. Baugh, *Refugees and asylees: 2016* (Washington, DC: Department of Homeland Security Office of Immigration Statistics, 2018). Available at <https://www.dhs.gov/immigration-statistics/refugees-asylees>.
3. Universal Declaration of Human Rights, G.A. Res. 217A (III) (1948), art. 14(1); Convention relating to the Status of Refugees, G.A. Res. 429(V) (1950), art. 33(1); *Refugee Act of 1980*, Public Law 96-212, *US Statutes at Large* 94, pp. 102-117 (1980).
4. S. L. Lustig, S. Kureshi, K. L. Delucchi, et al., "Asylum grant rates following medical evaluations of maltreatment among political asylum applicants in the United States," *Journal of Immigrant and Minority Health* 10 (2008), pp. 7-15.
5. K. C. McKenzie, J. Bauer, and P. P. Reynolds, "Asylum seekers in a time of record forced global displacement: The role of physicians," *Journal of General Internal Medicine* 34 (2019), pp. 137-143.
6. R. Mishori, A. Hannaford, I. Mujawar, et al., "'Their stories have changed my life': Clinicians' reflections on their experience with and their motivation to conduct asylum evaluations," *Journal of Immigrant and Minority Health* 18 (2016), pp. 210-218.
7. Office of the United Nations High Commissioner for Human Rights, *Istanbul protocol: Manual on the effective investigation and documentation of torture and other cruel, inhuman or degrading treatment or punishment*, Professional Training Series No. 8/Rev. 1 (2004). Available at <https://www.ohchr.org/Documents/Publications/training8Rev1en.pdf>.
8. McKenzie et al. (see note 5); Physicians for Human Rights, *Examining asylum seekers: A clinician's guide to physical and psychological evaluations of torture and ill-treatment* (Cambridge, MA: Physicians for Human Rights, 2012); HealthRight International, *Training manual for physicians and mental health professionals* (New York: HealthRight International, 2010); J. M. Peart, E. H. Tracey, and J. B. Lipoff, "The role of physicians in asylum evaluation: Documenting torture and trauma," *JAMA Internal Medicine* 176 (2016), p. 417; S. M. Meffert, K. Musalo, D. E. McNeil, et al., "The role of mental health professionals in political asylum processing," *Journal of the American Academy of Psychiatry and the Law* 38 (2010), pp. 479-489; V. Iacopino, "Medical evaluations of asylum seekers," *AMA Journal of Ethics*, September 2004; L. F. Goodman, G. W. Jensen, J. M. Galante, et al., "A cross-sectional investigation of the health needs of asylum seekers in a refugee clinic in Germany," *BMC Family Practice* 19 (2018), p. 64.
9. E. Scruggs, T. C. Guetterman, A. C. Meyer, et al., "An absolutely necessary piece: A qualitative study of legal perspectives on medical affidavits in the asylum process," *Journal of Forensic and Legal Medicine* 44 (2016), pp. 72-78; A. Pitman, "Medicolegal reports in asylum applications: A framework for addressing the practical and ethical challenges," *Journal of the Royal Society of Medicine* 103 (2010), pp. 93-97.
10. Pitman (see note 9).
11. McKenzie et al. (see note 5).
12. M. Rosenberg, R. Levinson, and R. McNeill, "Heavy odds," *Reuters Investigates* (October 17, 2017). Available at <https://www.reuters.com/investigates/special-report/usa-immigration-asylum>.
13. *Federal rules of evidence*, art. VII, rule 702. Available at <https://www.rulesofevidence.org/article-vii/rule-702>.



14. Office of the United Nations High Commissioner for Human Rights (see note 7); Physicians for Human Rights (2012, see note 8); HealthRight International (2010, see note 8); Iacopino (see note 8).
15. McKenzie et al. (see note 5); Physicians for Human Rights, *Focus areas: Persecution and asylum* (2018). Available at <https://phr.org/issues/asylum-and-persecution/#top>; HealthRight International, *Human Rights Clinic forensic evaluation services* (2018). Available at <https://healthright.org/forensic-evaluation-services>.
16. McKenzie et al. (see note 5); Physicians for Human Rights (2018, see note 15).
17. Iacopino (see note 8).
18. Office of the United Nations High Commissioner for Human Rights (see note 7).
19. Physicians for Human Rights (2012, see note 8); HealthRight International (2010, see note 8).
20. Office of the United Nations High Commissioner for Human Rights (see note 7).
21. Physicians for Human Rights (2012, see note 8); HealthRight International (2010, see note 8).
22. Meffert et al. (see note 8).
23. P. Sen, "The mental health needs of asylum seekers and refugees: Challenges and solutions," *BJPsych International* 13 (2016), pp. 30–32.
24. Meffert et al. (see note 8).
25. A. Prins, M. J. Bovin, D. J. Smolenski, et al., "The primary care PTSD screen for DSM-5 (PC-PTSD-5): Development and evaluation within a veteran primary care sample," *Journal of General Internal Medicine* 31 (2016), pp. 1206–1211; K. Kroenke, R. L. Spitzer, and J. B. W. Williams, "The PHQ-9: Validity of a brief depression severity measure," *Journal of General Internal Medicine* 16 (2001), pp. 606–613; E. B. Foa, C. P. McLean, Y. Zang, et al., "Psychometric properties of the Posttraumatic Stress Disorder Symptom Scale Interview for DSM-5 (PSSI-5)," *Psychological Assessment* 28 (2016), pp. 1159–1165.
26. American Psychiatric Association, *Diagnostic and statistical manual of mental disorders*, 5th ed. (Arlington: American Psychiatric Association, 2013).
27. Z. S. Nasreddine, N. A. Phillips, V. Bedirian, et al., "The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment," *Journal of the American Geriatrics Society* 53 (2005), pp. 695–699.
28. See, for example, M. Hutchinson and P. Dorsett, "What does the literature say about resilience in refugee people? Implications for practice," *Journal of Social Inclusion* 3 (2012), pp. 55–78.
29. Office of the United Nations High Commissioner for Human Rights (see note 7).
30. Physicians for Human Rights (2012, see note 8); HealthRight International (2010, see note 8); M. Peel and V. Iacopino, *The medical documentation of torture* (San Francisco: Greenwich Medical Media, 2002).
31. R. Park and J. Oomen, "Context, evidence and attitude: The case for photography in medical examinations of asylum seekers in the Netherlands," *Social Science and Medicine* 71 (2010), pp. 228–235.
32. H. Zonana, "Commentary: The role of forensic psychiatry in the asylum process," *Journal of the American Academy of Psychiatry and the Law* 38 (2010), pp. 499–501; J. Ramji-Nogales, A. Schoenholtz, and P. Schrag, "Refugee roulette: Disparities in asylum adjudication," *Stanford Law Review* 60 (2007), p. 95.
33. P. Hernández, D. Gangsel, and D. Engstrom, "Vicarious resilience: A new concept in work with those who survive trauma," *Family Process* 46 (2007), pp. 229–241.
34. Mishori et al. (see note 6); A. Joscelyne, S. Knuckney, M. L. Satterthwaite, et al., "Mental health functioning in the human rights field: Findings from an international internet-based study," *PLoS ONE* 10 (2015).
35. C. A. Morgan, "Psychiatric evaluations of asylum seekers: Is it ethical practice or advocacy?" *Psychiatry* 4 (2007), pp. 26–33; C. D. Chacko, "Regarding psychiatric evaluations of asylum seekers," *Psychiatry* 4 (2007), p. 17; S. L. Lustig, "Psychiatric evaluations of asylum seekers: It's both ethical practice and advocacy, and that's ok!" *Psychiatry* 4 (2007), pp. 17–18.
36. McKenzie et al. (see note 5).



# The Role of Gender in the Health and Human Rights Practices of Police: The SHIELD Study in Tijuana, Mexico

TERESITA ROCHA-JIMÉNEZ, MARIA LUISA MITTAL, IRINA ARTAMONOVA, PIETER BAKER, JAVIER CEPEDA, MARIO MORALES, DANIELA ABRAMOVITZ, ERIKA CLAIRGUE, ARNULFO BAÑUELOS, THOMAS PATTERSON, STEFFANIE STRATHDEE, AND LEO BELETSKY

## Abstract

Globally, punitive drug law enforcement drives human rights violations. Drug control tactics, such as syringe confiscation and drug-related arrests, also cascade into health harms among people who use drugs. The role of police officer characteristics in shaping such enforcement and measures to reform police practices remains underexamined. We evaluated gender differences in syringe confiscation and

---

TERESITA ROCHA-JIMÉNEZ, MA, PhD, is a research associate at the University of California San Diego's Division of Infectious Diseases and Global Public Health and a fellow at the Center for U.S.-Mexican Studies, University of California San Diego, USA.

MARIA LUISA MITTAL, MD, is a project scientist at the Division of Infectious Diseases and Global Public Health, University of California San Diego, USA.

IRINA ARTAMONOVA, MS, is a statistician at the University of California San Diego, USA.

PIETER BAKER, MPH, is a PhD student and research associate at the University of California San Diego and San Diego State University, USA.

JAVIER CEPEDA, MPH, PhD, is an assistant professor at the Division of Infectious Diseases and Global Public Health, University of California San Diego, USA.

MARIO MORALES, MA, is a research assistant at the Division of Infectious Diseases and Global Public Health, University of California San Diego, USA.

DANIELA ABRAMOVITZ, MS, is the principal statistician at the Division of Infectious Diseases and Global Public Health, University of California San Diego, USA.

ERIKA CLAIRGUE, MA, is a research program manager at the University of California San Diego, USA.

ARNULFO BAÑUELOS is a research liaison at the Secretaría de Seguridad Pública Municipal, department of special planning and projects, Tijuana, Mexico.

THOMAS PATTERSON, PhD, is a distinguished professor of psychiatry at the University of California San Diego, USA.

STEFFANIE STRATHDEE, PhD, is associate dean of global health sciences, Harold Simon Professor at the University of California San Diego Department of Medicine, and principal investigator at Project ESCUDO.

LEO BELETSKY, MPH, JD, is a professor at the School of Law and Bouvé College of Health Sciences, Northeastern University, and an associate adjunct professor at the University of California San Diego, USA.

Please address correspondence to Leo Beletsky. Email: l.beletsky@neu.edu.

Competing interests: None declared.

Copyright © 2019 Rocha-Jiménez, Mittal, Artamonova, et al. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

syringe-related arrest behaviors among municipal police officers in Tijuana, Mexico, where syringe possession is legal. In the context of the SHIELD Study focusing on aligning policing with harm reduction measures, our baseline sample covered municipal police officers who reported having occupational contact with syringes. We used multivariable logistic regression with robust variance estimation via a generalized estimating equation to identify correlates of syringe-related policing behaviors. Among respondent officers ( $n=1,555$ ), 12% were female. After considering possible confounding variables, such as district of service and work experience, female officers were significantly less likely to report confiscating syringes or arresting individuals for syringe possession. Consideration of officer gender is important in the design of interventions to improve the health and human rights of people who inject drugs and other highly policed groups, as well as measures to safeguard officer occupational safety. The feminization of law enforcement deserves special consideration as an imperative in reducing the public health harms of policing.

## Introduction

In the context of the global “war on drugs,” the creation and enforcement of punitive criminal policies have become the central state response to addressing drug-related harms.<sup>1</sup> Driven by evidence that these interventions are a driver of human rights violations that cascade into health harms, governments across the globe have made efforts to reform drug laws and attendant policing practices.<sup>2</sup> However, policing practices associated with the violation of drug users’ human rights (such as arbitrary detention, extrajudicial arrests, and the use of force) in numerous settings, including those with progressive drug policies, persist.<sup>3</sup> As officers enforce drug policy on the streets, individual factors (such as officers’ gender, assignment, and age) may contribute to their behavior in ways that shape health among people who use drugs. To date, little is known about the role of gender in the design of interventions to harmonize drug policies and their enforcement with health and human rights goals.<sup>4</sup>

Policing—the main task of which is to ensure public safety—has historically been viewed as a largely male profession. Meanwhile, the provision

of other policing-related services, such as organizational and administrative tasks, has been perceived as a feminine responsibility.<sup>5</sup> Based on these gender-determined roles within the policing structure, women have been underrepresented as street-level police officers and have experienced discrimination from their male counterparts when performing these roles.<sup>6</sup> The feminization of law enforcement in the United States, along with the entrance of other underrepresented groups into policing, gained broader support in the 1970s.<sup>7</sup> Since then, gender has been a topic of interest in criminal justice research, while women’s role in law enforcement has changed and expanded.<sup>8</sup>

Some research has analyzed the differences between, on the one hand, attitudes toward law enforcement and the use of force and, on the other, attitudes related to community service.<sup>9</sup> Previous research has found that female law enforcement officers (LEOs) are less likely to use excessive force than their male counterparts.<sup>10</sup> These gender differences are notable, especially when considering global efforts to reduce aggressive police practices and to promote community-oriented policing.

Community policing movements have

prompted researchers to explore the specific contributions that female officers may make to policing culture and how those unique attitudes or behaviors may contribute to other practices (such as health-promotion practices).<sup>11</sup> However, there is limited research on the gender differences in policing behaviors related to occupational safety, harm reduction, public health, and human rights. Since police practices play a critical role in shaping community health, it is important to understand the differences in police behavior through a gender lens. This is especially true for policing practices related to drug law enforcement.

Injection drug use is a major public health concern and a significant risk factor for infection by blood-borne diseases, such as HIV and hepatitis C.<sup>12</sup> Drug law enforcement practices surrounding injection drug use constitute an important structural determinant of HIV risk for people who inject drugs (PWID).<sup>13</sup> Policing practices such as syringe confiscation and syringe-related arrests have been previously associated with HIV and hepatitis C infections, as well risky injection behaviors among PWID, including syringe sharing, rushed injections, and injecting in public places.<sup>14</sup>

Police interactions with PWID vary worldwide, as does the frequency with which PWID are arrested or have their syringes confiscated. For instance, Robin Pollini and colleagues conducted a study in Tijuana and Ciudad Juárez, Mexico, where they found that 57% of participants reported ever being arrested for syringe possession.<sup>15</sup> Confiscation of and arrests for syringe possession frequently occur even in settings where syringe possession is legal.<sup>16</sup>

Tijuana is a strategic locale for the study of drug law enforcement practices given its high burden of drug use, its location at the US-Mexico border, and its drug policy context. The Tijuana-San Diego border is one of the busiest international border crossings in the world, drawing extensive commercial activity, including the exchange of goods, arms, and drugs, as well as high levels of drug-related violence.<sup>17</sup> Responding to this context, Tijuana has invested in one of the largest municipal police departments in the country, with approximately 2,100

active-duty LEOs, of whom 80% are male and 20% are female.<sup>18</sup>

Despite the legality of syringe possession and purchase under Mexican law, LEOs in Tijuana often confiscate syringes from PWID or detain them for syringe possession.<sup>19</sup> Such extrajudicial arrests and confiscations represent human rights violations and pose a significant public health risk, as they limit syringe availability for PWID.<sup>20</sup> There are only a few syringe-exchange programs in Tijuana, and the availability of syringes for PWID at any given time is highly constrained and inconsistent.<sup>21</sup> This gap between PWID's ability to possess and purchase syringes and the actual practices of street-level policing has critical public health implications in the city, including an elevated risk of HIV and hepatitis C transmission through syringe sharing.<sup>22</sup>

Drug law enforcement occurs primarily in defined geographic points in the city, such as the Zona Norte, a section of downtown (Zona Centro) Tijuana where HIV cases, shooting galleries, and drug selling are concentrated.<sup>23</sup> The Zona Norte is also known as a sex trade "tolerance zone," meaning that sex work is quasi-regulated through public health measures.<sup>24</sup> Tijuana has one of Mexico's largest PWID populations and the country's highest prevalence of injection drug use (for example, heroin and methamphetamine).<sup>25</sup> HIV prevalence in Tijuana is triple the national average (0.9% compared to 0.3%), and transmission remains concentrated among high-risk populations.<sup>26</sup>

While much is known about the HIV risk environment and policing practices in this particular locale, even there the role of gender in drug law enforcement practices has been largely unexplored.<sup>27</sup> More globally, the effect of gender on job-related behaviors that affect public health and occupational safety is a neglected topic of inquiry.<sup>28</sup> Gender differences as they relate to drug law enforcement are important to understand, for they may shape the design of interventions to improve the health and human rights of criminalized groups, as well as officer occupational safety. Thus, the objective of this study was to understand gender differences in syringe-related policing behaviors (namely, syringe confiscation and arrest for syringe possession) and



occupational health knowledge among LEOs in the Tijuana police force, controlling for place of assignment and other factors.<sup>29</sup>

## Methods

This paper examines the baseline data for Proyecto Escudo (Spanish for “shield”) a binational, multi-institutional research collaboration between public health, local government, and municipal law enforcement entities. Designed according to the SHIELD (safety and health integration in the enforcement of laws on drugs) police training model, this intervention aims to modify policing behaviors that place PWID and LEOs at risk of HIV transmission. The program’s methodology has been described elsewhere.<sup>30</sup> In short, the SHIELD training was delivered by a combination of peer instructors and multimedia covering occupational safety, drug policy provisions, and harm reduction topics. The curriculum uniquely bundled occupational safety (for example, needlestick and sharp injury prevention) with public health themes related to injection drug use. We trained approximately 85% (N=1,806) of all active-duty LEOs in the Tijuana municipal force between February 2015 and May 2016.

A total of 1,771 LEOs provided written informed consent and self-administered pre- and post-training surveys. The present analysis was limited to those who reported contact with syringes or needles (n=1,555). Before administering the baseline survey, trained interviewers conducted a pilot survey with several Tijuana police officers. Female and male officers provided feedback on cultural appropriateness and the perceived validity of the type of questions, language, and scales included in our behaviors and knowledge questionnaire.<sup>31</sup> The final version of our questionnaire was based on this feedback, as well as on previous research.

Officers’ contact with syringes was assessed by the following question: “While working in law enforcement, how often did you typically come into contact with needles or syringes during the past six months?” This self-reported variable was administered using a three-point Likert scale. LEOs who responded “frequently” or “sometimes” were in-

cluded in our analysis, while those who responded “never” were excluded.

Dependent variables included syringe-related policing behavior in the past six months—namely, confiscating someone’s needles or syringes or arresting someone for needle or syringe possession. Participants were asked, “How often have you confiscated needles or syringes?” and “How often have you arrested someone for syringe possession?” These variables were treated as dichotomous: one category included the responses “all the time” and “sometimes,” and the other included the responses “rarely” and “never.”

Independent variables included the following:

- *Sociodemographic characteristics*: We recorded participants’ age, gender, assigned district (for example, Zona Centro vs. other districts), education level, years in law enforcement, current assignment (for example, patrol or administrative), and current rank (for example, officer, supervisor, deputy, or chief).
- *Needlestick injuries*: Participants were asked if they had ever been stuck by a needle or syringe.
- *Occupational knowledge*: Participants were asked to indicate their level of agreement with the following statements about avoiding needlestick injuries: “You should not throw syringes into the trash” and “You should ask suspects to list any sharp items in their possession before searching them.” Participants were also asked to agree or disagree with the statements “If I get a needlestick injury while on duty, I know what to do” and “I am confident that I can keep from getting a needlestick injury while on duty.” Responses were measured on a four-point Likert scale and dichotomized as yes (“completely agree” and “agree”) or no (“neither agree nor disagree,” “disagree,” and “strongly disagree”).
- *Syringe-related policing behaviors in the past six months*: Participants were asked how often they engaged in the following behaviors: “confiscate needles or syringes without making an arrest,” “transport needles to present them to proper authorities,” “break a needle or syringe,” “have

a physical altercation with a drug user,” “arrest someone for heroin possession,” and “refer drug users to a social or health program.” Variables were dichotomized as yes (“all the time” and “sometimes”) or no (“rarely” and “never”). Participants were also asked to indicate their level of agreement with the statement “What I do to prevent needlestick injuries is similar to what other police officers do.” Responses were measured on a four-point Likert scale and dichotomized as yes (“completely agree” and “agree”) or no (“neither agree nor disagree,” “disagree,” and “strongly disagree”).

This project obtained ethical approvals from the Human Research Protections Program of the University of California San Diego, USA, and from the Ethics Committee of the University of Xochicalco School of Medicine in Tijuana, Mexico.

## Data analysis

Female and male LEOs who reported having contact with needles or syringes in the past six months were compared based on baseline characteristics. We used Pearson’s chi-squared test for gender comparisons involving categorical variables and the Wilcoxon rank-sum test for comparisons involving continuous variables.

We used simple and multivariable logistic regression with robust variance estimation to assess the association between gender and the primary outcomes (syringe confiscation and arrest for syringe possession). We also used simple logistic regression to identify potential covariates to control for in the multivariable models. We calculated odds ratios (OR), 95% confidence intervals (CI), and p-values to evaluate the aforementioned associations. Variables that were significant ( $p < 0.10$ ) in the simple logistic regression models were considered for inclusion in the final multivariable logistic regression models.<sup>32</sup> In the multivariable models, multicollinearity was assessed and ruled out by appropriate values of tolerance, variance inflation factors, and condition indexes. To ensure the integrity of the models, we assessed and ruled

out all possible interactions between the predictors. We used SAS software (version 9.4) to conduct our statistical analyses.

## Results

Among the 1,555 LEOs who reported having come into contact with syringes during the previous six months, 12.2% ( $n=190$ ) were female and 87.8% ( $n=1,365$ ) were male, with a median age of 35 (interquartile range [IQR]: 30–40) and 38 (IQR: 33–44), respectively (Table 1). While 79.6% ( $n=1,133$ ) of the sample reported having at least a high school education, females (85%) reported this at a higher proportion than males (79%;  $p=0.057$ ). Most of the participants were assigned as officers (85.5%;  $n=1,328$ ) and most were assigned to street patrol by car or foot (86.5%;  $n=1,341$ ) at the time the pre-training survey was conducted. Compared to male LEOs, female LEOs had spent fewer years working in law enforcement (median of 9.3 vs. 12 years;  $p < 0.001$ ).

Female LEOs were significantly less likely to be assigned to patrol work compared to their male counterparts (78.4% vs. 87.6%;  $p < 0.001$ ). Further, a higher percentage of female LEOs (21.6%) reported doing administrative tasks compared to their male counterparts (12.4%). Compared to male LEOs, a higher proportion of female LEOs reported ever having a needlestick injury (16.4% vs. 12.6%); 3.8% of female LEOs compared to 1.2% of male LEOs reported experiencing such an injury in the previous six months ( $p=0.015$ ). These differences were not statistically significant.

Male and female LEOs were also found to differ significantly with respect to occupational knowledge and policing behaviors. For instance, female LEOs demonstrated higher proficiency in some—but not all—knowledge measures related to needlestick injury prevention. For example, a higher percentage of female LEOs (97.9%) responded correctly that “to avoid a needlestick injury, you should ask suspects to list any sharp items in their possession before searching them,” compared to 92.9% of male LEOs ( $p=0.007$ ). However, a higher percentage of female LEOs responded incorrectly to the following item: “To avoid a needlestick in-

jury, you should not throw syringes into the trash” (90.5% vs. 85.2%;  $p=0.028$ ). Also, female LEOs demonstrated lower levels of self-efficacy to prevent or manage such injuries compared to their male counterparts, as evidenced by males responding more positively than females to the following state-

TABLE 1. Descriptive statistics and sociodemographic and occupational and safety characteristics of Tijuana police officers who reported coming into occupational contact with needles (n=1,555)

Characteristic	Total (n=1,555) n (%)	Female (n=190) n (%)	Male (n=1,365) n (%)	P-value
<b>Sociodemographics</b>				
Age (median, IQR+ range)	38 (33–43)	35 (30–40)	38 (33–44)	<0.001
Education				
Less than high school	291 (20)	26 (15)	265 (21)	0.057
High school or more	1133 (80)	148 (85)	985 (79)	
<b>Occupational and safety characteristics</b>				
Total years in law enforcement <sup>^</sup> (median, IQR+ range)	11 (8–18)	9.3 (3–12)	12 (9–18)	<0.001
Current rank				
District chief	17 (1.1)	2 (1.1)	15 (1.1)	0.066
Deputy	66 (4.2)	3 (1.6)	63 (4.6)	
Supervisor	85 (5.5)	15 (7.9)	70 (5.1)	
Officer	1,328 (85.5)	167 (87.9)	1,161 (85.1)	
Other	58 (3.7)	3 (1.6)	55 (4.0)	
Current assignment				
Patrol	1,341 (86.5)	149 (78.4)	1,192 (87.6)	0.009
Administrative	209 (13.5)	41 (21.6)	168 (12.4)	
Assignment in Zona Centro	218 (14.2)	21 (11.3)	197 (14.6)	0.262
Ever accidentally stuck by a needle	202 (13.0)	31 (16.4)	171 (12.6)	0.165
Since the beginning of the training <sup>*</sup> accidentally stuck by a needle	23 (1.5)	7 (3.8)	16 (1.2)	0.015
<b>Occupational knowledge</b>				
To avoid a needlestick injury, you should not throw syringes into the trash	1,398 (89.9)	162 (85.2)	1,236 (90.5)	0.028
To avoid a needlestick injury, you should ask suspects to list any sharp items in their possession before searching them	1,453 (93.5)	185 (97.9)	1,268 (92.9)	0.007
If I get a needlestick injury while on duty, I know what to do	1,056 (68.2)	112 (59.3)	944 (69.5)	0.006
I am confident that I can keep from getting a needlestick injury while on duty	1,191 (76.8)	129 (68.3)	1,062 (78)	0.004
<b>Syringe-related policing behaviors in the past six months</b>				
What I do to prevent needlestick injuries is similar to what other police officers do	1,070 (69.0)	106 (56.1)	964 (70.8)	<0.001
I have confiscated needles or syringes	1,181 (76.1)	121 (64.0)	1,060 (77.8)	<0.001
I have confiscated needles or syringes without making an arrest <sup>^^</sup>	633 (48.6)	49 (33.3)	584 (50.6)	<0.001
I have transported syringes to present them to the proper authorities	773 (49.8)	82 (43.4)	691 (50.7)	0.063
I have broken a needle or syringe	732 (47.2)	63 (33.3)	669 (49.1)	<0.001
I have arrested someone for syringe possession	990 (63.8)	99 (52.4)	891 (65.4)	0.001
I have had a physical altercation with a drug user	1,067 (69.0)	115 (61.2)	952 (70.1)	0.015
I have arrested someone for heroin possession	1,047 (67.5)	99 (52.4)	948 (69.6)	<0.001
I have referred people who use drugs to social or health programs	901 (58.1)	94 (49.7)	807 (59.3)	0.015

+ Interquartile range

\* March 2015

<sup>^</sup> n=1,424

<sup>^^</sup> n=1,302

ments: “If I get a needlestick injury while on duty, I know what to do” (69.5% vs. 59.3%;  $p=0.006$ ), “I am confident that I can keep from getting a needlestick injury while on duty” (78% vs. 68.3%;  $p=0.004$ ), and “What I do to prevent needlestick injuries is similar to what other police officers do” (70.8% vs. 56.1%;  $p<0.001$ ) (Table 1). Almost 60% of the officers surveyed reported referring people who use drugs to a social or health program in the past six months (50% of female respondents and 60% of male respondents;  $p=0.015$ ).

Even though males appeared to be more confident in their ability to handle syringes, female LEOs demonstrated policing behaviors that are more consistent with public health and occupational safety imperatives (Tables 1 and 2). Compared to male LEOs, female LEOs were less likely to report having recently (past six months) confiscated

syringes (64% vs. 77.8%;  $p<0.001$ ), less likely to report having confiscated syringes without an arrest (33.3% vs. 50.6%;  $p<0.001$ ), less likely to report having arrested someone for syringe possession (52.4% vs. 65.4%;  $p<0.007$ ), and less likely to report having arrested someone for heroin possession (52.4% vs. 69.6%;  $p<0.001$ ). Additionally, compared to their male counterparts, female LEOs were less likely to break a needle or syringe (33.3% vs. 49.1%;  $p<0.001$ ) and less likely to have an altercation with a person who injects drugs (61.2% vs. 70.1%;  $p=0.015$ ).

Using multivariable modeling, we analyzed syringe confiscation and arrest for syringe possession as the main outcomes, with gender as the main predictor. In the final model, we included covariates such as assigned district (Zona Centro vs. others) and current assignment (patrol vs. other work), as well as a continuous variable for work experience

TABLE 2. Descriptive statistics and factors associated with confiscating needles and arresting someone for needles of Tijuana police officers who reported occupational contact with needles (n=1,555)

Characteristic	Confiscated needles or syringes					Arrested someone for needles or syringes				
	Always/sometimes (n=740)	Rarely/never (n=811)	Odds ratio	95% CI	P-value*	Always/sometimes (n=740)	Rarely/never (n=811)	Odds ratio	95% CI	P-value*
Gender: female (vs. male) n (%)	66 (8.9)	123 (15.2)	0.55	(0.40–0.75)	<0.001	60 (9.5)	129 (14.1)	0.64	(0.46–0.89)	0.007
Mean age (standard deviation)	37.7 (8.4)	39.0 (9.0)	0.98	(0.97–0.99)	0.004	37.6 (8.4)	38.8 (8.9)	0.98	(0.97–1.00)	0.007
Commissioned district: Zona Centro (vs. other) n (%)	157 (21.3)	61 (7.6)	3.28	(2.39–4.50)	<0.001	144 (22.9)	74 (8.2)	3.33	(2.64–4.50)	<0.001
Education: at least high school (vs. less) n (%)	560 (81.4)	572 (77.9)	1.24	(0.96–1.61)	0.105	461 (79.2)	670 (79.8)	0.97	(0.74–1.26)	0.799
Mean number of years in law enforcement <sup>^</sup> (standard deviation)	12.1 (7.5)	13.6 (8.4)	0.98	(0.97–0.99)	<0.001	12.3 (7.8)	13.3 (8.1)	0.98	(0.97–1.00)	0.023
Current assignment: patrol (vs. other) n (%)	693 (93.6)	645 (80.0)	3.70	(2.63–5.26)	<0.001	598 (94.5)	740 (81.1)	4.00	(2.70–5.88)	<0.001
Rank: officer (vs. other) n (%)	650 (87.8)	674 (83.2)	1.46	(1.09–1.94)	0.010	559 (88.3)	765 (83.4)	1.50	(1.11–2.02)	0.008

<sup>^</sup>Including work in Tijuana law enforcement and other agencies

\*Yielded by univariate logistic regressions

(number of years in the police force). In the first multivariable model (Table 3), we found that female LEOs were half as likely to confiscate syringes compared to male LEOs (95% CI: 0.37–0.73;  $p < 0.002$ ). In the second multivariable model (Table 3), we found that female LEOs had marginally lower odds of arresting someone for syringe possession compared to their male counterparts (OR=0.71; 95% CI: 0.51–1.00;  $p = 0.049$ ).

## Discussion

In this large study of LEOs in Tijuana, Mexico, we found that occupational knowledge and behaviors that affect public health differed significantly between male and female LEOs. These findings align with previous studies' findings on gender differences in policing.<sup>33</sup> Some of these studies found that female LEOs reported higher rates of listening skills and community engagement, whereas male LEOs reported higher rates of physical force and strength and dealing with local issues using a more traditional approach (such as through the use of force). In view of the fact that the behaviors studied here (syringe confiscation and syringe-related arrests) are practices detrimental to both health and human rights, the more rights-aware behavior of female LEOs may represent positive contributions by female LEOs to occupational safety and public health in Tijuana.<sup>34</sup> These important differences in behavior between female and male LEOs persisted despite lower levels of female officers' occupational

safety self-efficacy (for example, "If I get a needlestick injury while on duty, I know what to do") and knowledge of some risky behaviors (for example, "To avoid a needlestick injury, you should not throw syringes into the trash"). These differences between female and male LEOs also persisted when we controlled for the geographical setting of deployment and other factors in the final models (Table 3). These differences in knowledge and behaviors between male and female LEOs may be partly a response to the gender-determined roles within the Mexican police force, where women have been underrepresented and undertrained and often face opposition and discrimination from their male counterparts.<sup>35</sup>

Gender differences in self-reported behaviors observed here may also be explained by organizational factors, such as male police partners choosing to take on more aggressive and risky tasks.<sup>36</sup> Additionally, a previous analysis conducted by Mario Morales and colleagues found that "LEOs may feel pressure from superiors or peers to meet arrest or other encounter quotas."<sup>37</sup> If this pressure is experienced differentially among males and females, it could account for some of these differences in behavior. Nevertheless, these findings provide a useful springboard for future research examining measures to improve public health, scale up harm reduction practices, and protect the human rights of people who use drugs.<sup>38</sup>

In this context, female LEOs may be more accepting and amenable to implement practices that are aligned with human rights and harm re-

TABLE 3. Multivariable analysis of confiscating needles or syringes and arresting someone for needle or syringe possession of Tijuana police officers who reported occupational contact with needles (n=1,551)

	Confiscating needles or syringes (previous six months)		
Effect	AOR	95% CI	P-value
Female vs. male	0.52	0.37–0.73	<0.002
Zona Centro vs. other district	3.04	2.18–4.23	<0.001
Patrol vs. other duty	3.11	2.15–4.50	<0.001
Less time in law enforcement (<5 years or less)	1.13	1.05–1.21	0.006
	Arresting someone for needle or syringe possession (previous six months)		
Effect	AOR	95% CI	P-value
Female vs. male	0.71	0.51–1.00	0.049
Zona Centro vs. other district	3.08	2.28–4.17	<0.001
Patrol vs. other duty	3.61	2.44–5.35	<0.001



duction principles.<sup>39</sup> By engaging in extrajudicial police practices with less frequency, female officers may help promote community trust, public health, and occupational health.<sup>40</sup> It is notable that a higher percentage of female LEOs reported ever having a needlestick injury (16.4% vs. 12.6%) or recently experiencing such an injury (that is, in the past six months) (3.8% vs. 1.2%) compared to male LEOs. Although these differences did not reach statistical significance, further analysis is needed to explore the possible sources of this vulnerability among female LEOs, as well as the possibility of reporting bias across a gender gradient.<sup>41</sup>

Lastly, it is important to mention that a high percentage of the overall sample (60%) reported referring people who use drugs to health and social programs. Female LEOs were significantly less likely to report referring such individuals compared to their male counterparts (50% vs. 60%;  $p < 0.015$ ). Previous studies have documented the scarcity of available drug treatment programs in Tijuana.<sup>42</sup> Furthermore, they have found that some available programs may include involuntary drug treatment, which has been found to violate the human rights of people who use drugs and to have direct detrimental outcomes for their health.<sup>43</sup> In this context, less frequent referrals may paradoxically signal better alignment with health and human rights principles among female officers. At a time when increased focus is placed on building “warm hand-off” and other referral schemes between police and substance use treatment providers, this question warrants further study.

## Limitations

This analysis is not without limitations. The data we collected were based on self-reporting, and thus social desirability and recall bias may have led to an underreporting of specific behaviors or events (such as syringe-related arrests) or to an over-reporting of other behaviors (such as referrals to health and social programs). However, the fact that the surveys were self-administered may have reduced the influence of social desirability. Additionally, the data analyzed for this study were collected prior to

the police education program, meaning that LEOs who were unaware that some of their behaviors were detrimental to public health might have been inclined to answer honestly. The Likert scale may have introduced subjectivity in officers’ responses to certain behaviors, considering that frequency in the past six months may have been interpreted differently among respondents. However, to limit this potential effect, we included an ordinal scale instead of a numeric one, as recommended by key stakeholders during our pilot survey. Furthermore, we used such a scale to account for the fact that officers rotate activities, and we expected that the frequency included could be generalized over a previous six-month period. We did not expect the interpretation of our survey questions to have differed between male and female respondents. However, this possibility should be considered when designing studies aiming to assess behavioral differences between female and male officers.

Because our analysis was limited to those LEOs who reported coming into contact with syringes during their policing activities, our findings may not be generalizable to LEOs with other duties within the police force or to other police forces in Mexico. Even though we controlled for current duties and assignment locations (for example, Zona Norte vs. other districts) in our final models, we were unable to assess officers’ exact rotation frequency (for example, days, weeks, or months). Thus, acute changes in officers’ duties may not be accounted for.

## Conclusion

After accounting for officers’ assignment locations and other factors, we found that female LEOs had significantly lower odds of confiscating syringes and arresting PWID for possessing needles or syringes compared to their male counterparts. These findings provide an important foundation for future research seeking to better understand and calibrate interventions that realign policing with health and human rights imperatives in drug law enforcement and other contexts.<sup>44</sup> Additionally, our study may provide guidance for broader policing

research that seeks to assess potential differences among female and male LEOs. Feminization of policing as a public health imperative deserves closer attention from researchers, policing managers, and policy makers.<sup>45</sup>

## Acknowledgments

This work was supported by the Open Society Foundations Latin America Program (grant numbers OR2013-11352 and OR2014-18327), the National Institute on Drug Abuse (grant number R01DA039073), the Fogarty International Center of the National Institutes of Health (award numbers D43TW008633, R25TW009343, T32DA023356, and K01DA043421), and the University of California San Diego Center for AIDS Research (National Institute of Allergy and Infectious Diseases international pilot grant 5P30AI036214). Teresita Rocha-Jiménez was supported by a joint grant from Mexico's Consejo Nacional de Ciencia y Tecnología and the University of California Institute for Mexico and the United States (396237). She was also supported by the University of California San Diego Center for U.S.-Mexican Studies through a visiting fellowship.

## References

1. P. Bourgois, "The moral economies of homeless heroin addicts: Confronting ethnography, HIV risk, and everyday violence in San Francisco shooting encampments," *Substance Use and Misuse* 33/11 (1998), pp. 2323-2351; United Nations Human Rights Council, *Resolution 33/9: The right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, UN Doc. A/HRC/RES/33/9 (2016); R. Lines and J. Hannah, "New UN guidelines to mainstream human rights in the global drugs debate," *Conversation* (March 15, 2019). Available at <https://theconversation.com/new-un-guidelines-to-mainstream-human-rights-in-the-global-drugs-debate-113221>.
2. Lines and Hannah (see note 1); F. Godlee and R. Hurley, "The war on drugs has failed: Doctors should lead calls for drug policy reform," *BMJ: British Medical Journal* 355 (2016).
3. Human Rights Watch, *Philippines: Events of 2018* (New York: Human Rights Watch, 2018); C. Rafful, M. E. Medina-Mora, P. González-Zúñiga, et al., "Somebody is gonna be hurt': Involuntary drug treatment in Mexico," *Medical Anthropology* (2019); R. Bluthenthal, J. Lorvick, A. Kral, et al., "Collateral damage in the war on drugs: HIV risk behaviors among injection drug users," *International Journal of Drug Policy* 10/1 (1999), pp. 25-38.
4. M. Morales, C. Rafful, T. Gaines, et al., "Factors Associated with extra-judicial arrest for syringe possession: Results of a department-wide survey of municipal police in Tijuana, Mexico," *BMC International Health and Human Rights* 18/36 (2018), pp. 1-10; R. W. Benson, "Changing police culture: The sine qua non of reform," *Loyola of Los Angeles Law Review* 34 (2000), p. 681; M. Poteyeva and I. Y. Sun, "Gender differences in police officers' attitudes: Assessing current empirical evidence," *Journal of Criminal Justice* 37/5 (2009), pp. 512-522; C. Dejong, "Gender differences in officer attitude and behavior," *Women and Criminal Justice* 15/3-4 (2005), pp. 1-32.
5. Poteyeva and Sun (see note 4); J. Brown, "From cult of masculinity to smart macho: Gender perspectives on police occupational culture," in M. O'Neill, M. Marks, and A. Singh (eds), *Police occupational culture: Sociology of crime, law and deviance* (United States: Emerald Group Publishing Limited, 2007), pp. 205-226; S. E. Martin, "Police force or police service? Gender and emotional labor," *Annals of the American Academy of Political and Social Science* 561/1 (1999), pp. 111-126; M. G. Brecci, "Female officers on patrol: Public perceptions in the 1990's," *Journal of Crime and Justice* 20/2 (1997), pp. 153-165.
6. Brown (see note 5); C. A. Franklin, "Male peer support and the police culture: Understanding the resistance and opposition of women in policing," *Women and Criminal Justice* 16/3 (2007), pp. 1-25.
7. Poteyeva and Sun (see note 4); S. L. Miller, "Intersecting gender with community policing: A review of history existing theories, and research," in S. L. Miller (ed), *Gender and community policing: Walking the talk* (Boston: Northeastern University Press, 1999), pp. 65-98.
8. Dejong (see note 4); Brown (see note 5); Franklin (see note 6).
9. Poteyeva and Sun (see note 4); Dejong (see note 4); Franklin (see note 6); H. Goldstein, "Toward community-oriented policing: Potential, basic requirements, and threshold questions," *Crime and Delinquency* 33/1 (1987), pp. 6-30; E. A. Paoline III, S. M. Myers, and R. E. Worden, "Police culture, individualism, and community policing: Evidence from two police departments," *Justice Quarterly* 17/3 (2000), pp. 575-605; S. Lawrence and M. Bobby, "What is community policing?," in S. Lawrence and M. Bobby (eds), *What works in community policing? A best practices context for measure y efforts* (Berkeley: Chief Justice Earl Warren Institute on Law and Social Policy, 2013), pp. 5-6; L. W. Brooks, A. Piquero, and J. Cronin, "Police officer attitudes concerning their communities and their roles: A comparison of two suburban police departments," *American Journal of Police* 12/3 (1993), pp. 115-139.

10. Dejong (see note 4); Goldstein (see note 9); K. A. Lonsway, "Are we there yet? The progress of women in one large law enforcement agency," *Women and Criminal Justice* 18/1-2 (2007), pp. 1-48; K. A. Lonsway, *Hiring and retaining more women: The advantages to law enforcement agencies* (Los Angeles: National Center for Women and Policing, 2000), pp. 2-14.
11. Poteyeva and Sun (see note 4); Dejong (see note 4); Lonsway (2007, see note 10); Lonsway (2000, see note 10).
12. Bluthenthal et al. (see note 3); C. Magis-Rodríguez, K. C. Brouwer, S. Morales, et al., "HIV prevalence and correlates of receptive needle sharing among injection drug users in the Mexican-US border city of Tijuana," *Journal of Psychoactive Drugs* 37/3 (2005), pp. 333-339; B. M. Mathers, L. Degenhardt, B. Phillips, et al., "Global epidemiology of injecting drug use and HIV among people who inject drugs: a systematic review," *Lancet* 372/9651 (2008), pp. 1733-1745.
13. Bluthenthal et al. (see note 3); J. A. Cepeda, S. A. Strathdee, J. Arredondo, et al., "Assessing police officers' attitudes and legal knowledge on behaviors that impact HIV transmission among people who inject drugs," *International Journal of Drug Policy* 50 (2017), pp. 56-63.
14. L. Beletsky, R. Lozada, T. Gaines, et al., "Syringe confiscation as an HIV risk factor: The public health implications of arbitrary policing in Tijuana and Ciudad Juárez, Mexico," *Journal of Urban Health* 90/2 (2013), pp. 284-298; K. Hayashi, L. Ti, J. A. Buxton, et al., "The effect of exposures to policing on syringe sharing among people who inject drugs in Bangkok, Thailand," *AIDS and Behavior* 17/8 (2013), pp. 2615-2623; C. L. Miller, M. Firestone, R. Ramos, et al., "Injecting drug users' experiences of policing practices in two Mexican-US border cities: Public health perspectives," *International Journal of Drug Policy* 19/4 (2008), pp. 324-331; R. A. Pollini, K. C. Brouwer, R. M. Lozada, et al., "Syringe possession arrests are associated with receptive syringe sharing in two Mexico-US border cities," *Addiction* 103/1 (2008), pp. 101-108; D. Werb, E. Wood, W. Small, et al., "Effects of police confiscation of illicit drugs and syringes among injection drug users in Vancouver," *International Journal of Drug Policy* 19/4 (2008), pp. 332-338; E. Wood, M. W. Tyndall, P. M. Spittal, et al., "Factors associated with persistent high-risk syringe sharing in the presence of an established needle exchange programme," *AIDS* 16/6 (2002), pp. 941-943; T. Rhodes, A. Judd, L. Mikhailova, et al., "Injecting equipment sharing among injecting drug users in Togliatti City, Russian Federation: Maximizing the protective effects of syringe distribution," *JAIDS: Journal of Acquired Immune Deficiency Syndromes* 35/3 (2004), pp. 293-300.
15. Pollini et al. (see note 14).
16. Werb et al. (2008, see note 14); Wood et al. (see note 14); S. A. Strathdee, T. B. Hallett, N. Bobrova, et al., "HIV and risk environment for injecting drug users: The past, present, and future," *Lancet* 376/9737 (2010), pp. 268-284; S. A. Strathdee, D. M. Patrick, C. P. Archibald, et al., "Social determinants predict needle-sharing behaviour among injection drug users in Vancouver, Canada," *Addiction* 92/10 (1997), pp. 1339-1347.
17. R. Willoughby, "Crouching fox, hidden eagle: Drug trafficking and transnational security; A perspective from the Tijuana-San Diego border," *Crime, Law and Social Change* 40/1 (2003), pp. 113-142; L. Astorga and D. A. Shirk, *Drug trafficking organizations and counter-drug strategies in the US-Mexican context* (San Diego: Center for U.S.-Mexican Studies, 2010).
18. D. Shirk, M. E. Suárez de Garay, O. Rodríguez Ferreira, et al., *Justiciabarómetro: Diagnóstico de los operadores del sistema de justicia; Tijuana, Mexico* (San Diego: Woodrow Wilson Center, University of San Diego, Universidad de Guadalajara, 2015).
19. Morales et al. (see note 4); Cepeda et al. (see note 13); Pollini et al. (see note 14); Gobierno Municipal de XVII Ayuntamiento de Tijuana, *Bando de Policía y Gobierno para el municipio de Tijuana, Baja California* (Tijuana, Baja California: Gobierno Municipal de Tijuana, 2002).
20. Morales et al. (see note 4); United Nations Human Rights Council, *Access to justice for the right to housing*, UN Doc. A/HRC/40/61 (2019).
21. D. M. Smith, D. Werb, D. Abramovitz, et al., "Predictors of needle exchange program utilization during its implementation and expansion in Tijuana, Mexico," *American Journal on Addictions* 25/2 (2016), pp. 118-124.
22. Morales et al. (see note 4); Cepeda et al. (see note 13); Beletsky et al. (see note 14).
23. K. C. Brouwer, J. R. Weeks, R. Lozada, et al., "Integrating GIS into the study of contextual factors affecting injection drug use along the Mexico/US border," in Y. F. Thomas, D. Richardson, and I. Cheung (eds), *Geography and drug addiction* (United States: Springer, 2008), pp. 27-42; M. L. Rusch, K. C. Brouwer, R. Lozada, et al., "Distribution of sexually transmitted diseases and risk factors by work locations among female sex workers in Tijuana, Mexico," *Sexually Transmitted Diseases* 37/10 (2010), pp. 608-614.
24. N. Sirotin, S. A. Strathdee, R. Lozada, et al., "A comparison of registered and unregistered female sex workers in Tijuana, Mexico," *Public Health Reports* 125/Suppl 4 (2010), p. 101; N. Sirotin, S. A. Strathdee, R. Lozada, et al., "Effects of government registration on unprotected sex amongst female sex workers in Tijuana, Mexico," *International Journal of Drug Policy* 21/6 (2010), pp. 466-470.
25. Magis-Rodríguez et al. (see note 12); P. Case, R. Ramos, K. C. Brouwer, et al., "At the borders, on the edge: Use of injected methamphetamine in Tijuana and Ciudad Juárez, Mexico," *Journal of Immigrant and Minority Health* 10/1 (2008), pp. 23-33; Secretaría de Salud, Comisión Nacional contra las Adicciones, Instituto Nacional de Salud Pública, et al., *Encuesta nacional de consumo de drogas, alcohol y tabaco 2016-2017* (Mexico City: Instituto Nacional de Psiquiatría Ramón de la Fuente Muñiz, 2017).

26. Magis-Rodríguez et al. (see note 12); S. A. Strathdee, C. Magis-Rodríguez, V. M. Mays, et al., "The emerging HIV epidemic on the Mexico-US border: An international case study characterizing the role of epidemiology in surveillance and response," *Annals of epidemiology* 22/6 (2012), pp. 426–438.
27. Morales et al. (see note 4).
28. Poteyeva and Sun (see note 4); Dejong (see note 4); Brown (see note 5); Lonsway (2007, see note 10); S. E. Martin, "Policewomen and policemen: Occupational role dilemmas and choices of female officers," *Journal of Police Science and Administration* 7/3 (1979), pp. 314–323.
29. Smith et al. (see note 21); D. Werb, S. A. Strathdee, A. Vera, et al., "Spatial patterns of arrests, police assault and addiction treatment center locations in Tijuana, Mexico," *Addiction* 111/7 (2016), pp. 1246–1256.
30. S. A. Strathdee, J. Arredondo, T. Rocha, et al., "A police education programme to integrate occupational safety and HIV prevention: Protocol for a modified stepped-wedge study design with parallel prospective cohorts to assess behavioural outcomes," *BMJ Open* 5/8 (2015), pp. e008958; J. Arredondo, L. Beletsky, P. Baker, et al., "Interactive versus video-based training of police to communicate syringe legality to people who inject drugs: The SHIELD Study, Mexico, 2015–2016," *American Journal of Public Health* 109 (2019), pp. 921.
31. Morales et al. (see note 4); Cepeda et al. (see note 13); Strathdee et al. (see note 30); M. L. Mittal, L. Beletsky, E. Patiño, et al., "Prevalence and correlates of needle-stick injuries among active duty police officers in Tijuana, Mexico," *Journal of the International AIDS Society* 19 (2016), pp. 20874; L. Beletsky, R. Thomas, N. Shumskaya, et al., "Police education as a component of national HIV response: Lessons from Kyrgyzstan," *Drug and Alcohol Dependence* 132 (2013), pp. S48–S52.
32. D. W. Hosmer Jr., S. Lemeshow, and R. X. Sturdivant, *Applied logistic regression* (New Jersey: John Wiley and Sons, 2013).
33. Poteyeva and Sun (see note 4); Dejong (see note 4); Martin (1999, see note 5); Martin (1979, see note 28); W. P. McCarty, J. "Solomon" Zhao, and B. E. Garland, "Occupational stress and burnout between male and female police officers: Are there any gender differences?," *Policing: An International Journal of Police Strategies and Management* 30/4 (2007), pp. 672–691.
34. Beletsky et al. (see note 14); Werb et al. (2008, see note 14).
35. Brown (see note 5); Franklin (see note 6).
36. Cepeda et al. (see note 13).
37. Morales et al. (see note 4).
38. Bluthenthal et al. (see note 3); Goldstein (see note 9); Lawrence and Bobby (see note 9); M. M. Müller, "Community policing in Latin America: Lessons from Mexico City," *European Review of Latin American and Caribbean Studies* (2010), pp. 21–37; M. R. Decker, A.-L. Crago, S. K. Chu, et al., "Human rights violations against sex workers: bBrden and effect on HIV," *Lancet* 385/9963 (2015), pp. 186–199; Cepeda et al. (see note 13).
39. Breci (see note 5); Martin (1979, see note 28).
40. Cepeda et al. (see note 13); K. F. Hawk, F. E. Vaca, and G. D'Onofrio, "Focus: Addiction: Reducing fatal opioid overdose: Prevention, treatment and harm reduction strategies," *Yale Journal of Biology and Medicine* 88/3 (2015), p. 235.
41. Strathdee et al. (see note 30).
42. Werb et al. (2016, see note 29).
43. Rafful et al. (see note 3).
44. Beletsky et al. (see note 14); Pollini et al. (see note 14).
45. Miller et al. (see note 14); Dejong (see note 5).

# The Impact of the Presidential Alternative Treatment Program on People Living with HIV and the Gambian HIV Response

SARAH L. BOSHA, MICHELLE ADENIYI, JENNA IVAN, ROYA GHIASEDDIN, FABAKARY MINTEH, LAMIN F. BARROW, AND REX KUYE

## Abstract

In January 2007, former president of The Gambia Yahya Jammeh created the Presidential Alternative Treatment Program (PATP), which introduced a fraudulent “HIV cure.” PATP and the fraudulent HIV herbal cure (PATP cure) were widely advertised in state media through patient testimonials and specially produced broadcasts of Jammeh administering treatment, enticing people living with HIV to join the program. Jammeh faced little to no opposition from within The Gambia. Due to the great power and influence he wielded, PATP was nothing short of a health dictatorship. This paper argues that PATP and the PATP cure violated the human rights of people living with HIV in The Gambia and compromised HIV health service delivery. In addition, during PATP’s 10-year operation, the global health community was derelict in its duty to stop Jammeh’s promotion and use of the PATP cure and to protect people living with HIV.

---

SARAH L. BOSHA, LLBS, LLM, is an assistant teaching professor of global health and human rights at the Eck Institute for Global Health, University of Notre Dame, and a legal and research associate at AIDS-Free World, USA.

MICHELLE ADENIYI, BA, MSGH, is a graduate of the Masters in Global Health program at the Eck Institute for Global Health, University of Notre Dame, USA.

JENNA IVAN, BA, MSGH, is a graduate of the Masters in Global Health program at the Eck Institute for Global Health, University of Notre Dame, USA.

ROYA GHIASEDDIN is a professor at the Department of Applied and Computational Mathematics and the Eck Institute for Global Health, University of Notre Dame, USA.

FABAKARY MINTEH, HND, BSc, is a graduate assistant in the Department of Public and Environmental Health, School of Medicine and Allied Health Sciences, University of The Gambia.

LAMIN F. BARROW, HND, BSc, is a graduate assistant in the Department of Public and Environmental Health, School of Medicine and Allied Health Sciences, University of The Gambia.

REX KUYE, MSc, MPH, PhD, FWAPCEH, is an associate professor and head of the Department of Public and Environmental Health, School of Medicine and Allied Health Sciences, University of The Gambia.

Competing interests: None declared.

Please address correspondence to Sarah L. Bosh. Email: sbosha@nd.edu.

Copyright © 2019 Bosh, Adeniyi, Ivan, et al. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original author and source are credited.



## Introduction

In past years, fraudulent HIV cures supported by the highest levels of state have emerged in various countries.<sup>1</sup> In January 2007, then Gambian president and dictator Yahya Jammeh announced that he had received a “mandate from God” to create an HIV and AIDS herbal cure from seven herbs found in the Qur’an.<sup>2</sup> He announced, “Mine is not an argument, mine is a proof. It’s a declaration. I can cure AIDS and I will.”<sup>3</sup>

Jammeh created the Presidential Alternative Treatment Program (PATP) to distribute his fraudulent HIV cure (PATP cure). PATP operated from 2007 to 2016, when Jammeh was voted out of power.<sup>4</sup> Jammeh refused to have his cure subjected to scientific testing for efficacy and safety.<sup>5</sup> Instead, he sent the blood samples of his first nine patients to a laboratory in Senegal to prove that the PATP cure worked. Although the results showed only the CD4 levels of the patients, Jammeh argued that these levels were proof of efficacy. Officials at the Senegalese university who conducted the testing refuted Jammeh’s claim, explaining that no conclusion of the effectiveness of his herbal cure had been made.<sup>6</sup> They remarked, “It’s dishonest of the Gambian government to use our results in this way.”<sup>7</sup>

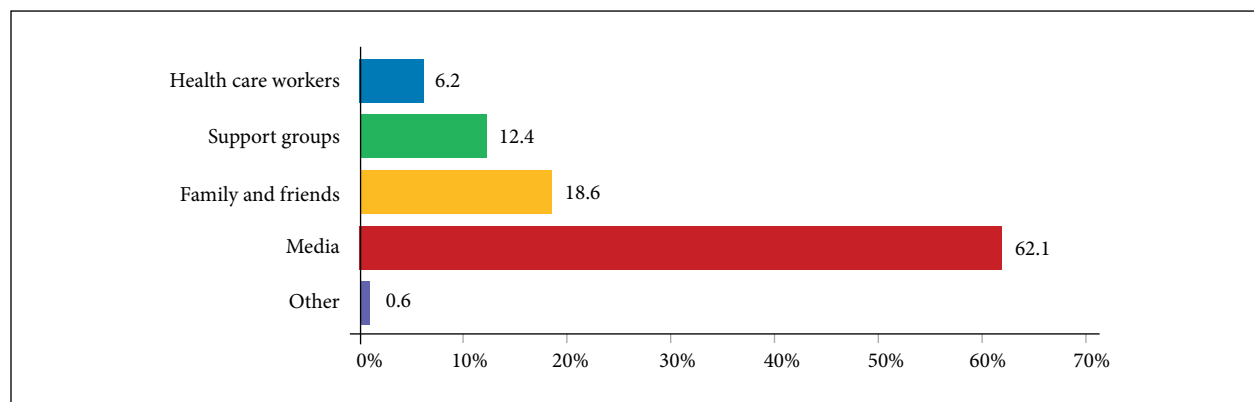
Jammeh has no medical training, holds only a high school diploma, and is from a family well known in The Gambia for herbal remedies.<sup>8</sup> When he first began PATP, it was to cure HIV and AIDS. Later, Jammeh’s PATP claimed to also cure diabetes, infertility, and cancer, among other diseases. In

this paper, PATP is used to refer to the program’s focus on people living with HIV, and the PATP cure refers exclusively to the unscientifically proven and untested HIV “cure” promoted by Jammeh.

Jammeh claimed that his PATP cure could eradicate HIV from the body in just three days. At the time of the introduction of his PATP cure in 2007, the number of people living with HIV in the Gambia was 18,000.<sup>9</sup> This number rose steadily to 21,000 by 2018.<sup>10</sup>

The first cohort of PATP patients was a mixture of people who chose to enter PATP and people who joined under duress. PATP patient cohorts were grouped according to their date of arrival and were given strict instructions for their participation, including discontinuation of antiretroviral medications and abstention from sex, caffeine, alcohol, and kola nuts.<sup>11</sup> Patients were also forbidden from eating or drinking anything from outside the PATP facilities or receiving visitors.<sup>12</sup> In violation of privacy rights and patient confidentiality, the names, faces, CD4 counts, and viral loads of patients were published on an official website promoting and providing information about the program.<sup>13</sup> It is unknown exactly how many people living with HIV enrolled in PATP. Tasmir Mbowe, former director general and self-proclaimed clinical expert of PATP, speaking before the Janneh Commission in 2018, claimed that only 311 HIV positive people enrolled in PATP during its 10 years.<sup>14</sup> The claim of only 311 patients contradicted Mbowe’s statements to the Gambian press in 2016, when he claimed

FIGURE 1. Method of first hearing about the Presidential Alternative Treatment Program among people living with HIV in The Gambia



that 9,000 patients had been given herbal cures for various ailments, with the majority of them being treated for HIV.<sup>15</sup> In 2009, researchers reported that more than 200 HIV-positive people had been treated in the program.<sup>16</sup> The figures are unknown and debatable because the records of the exact numbers of those enrolled and who died in PATP have not been released. It is unclear whether proper records of patients' arrivals, discharges, or deaths were even kept during the duration of PATP.

Mbowe's medical qualifications legitimized PATP, as he publicly spoke in favor of the alleged success of the PATP cure.<sup>17</sup> As the program's director general, he was responsible for recruiting patients.<sup>18</sup> Not all Gambian officials in the health sector approved of PATP. For example, two individuals—the director and the administrator of the National AIDS Secretariat—resigned in protest of the PATP cure.<sup>19</sup> Jammeh appointed a new director of the secretariat, who saw “the President's treatment as ‘complementary’ to conventional [antiretroviral] care” and was careful not to openly or directly oppose [PATP], arguing that Jammeh's support was necessary to halt HIV and AIDS prevalence rates.”<sup>20</sup>

Internationally, opposition to Jammeh was weak and failed to protect people living with HIV in The Gambia from the PATP cure. The United Nations (UN) responded to the PATP cure by issuing a statement through its United Nations Development Programme country director, Fadzai Gwaradzimba, in February 2007.<sup>21</sup> This statement challenged Jammeh to subject the cure to testing by a team of international experts and urged people living with HIV “to continue to comply with their treatment regimens while the efficacy of the new treatment is being assessed.”<sup>22</sup> For that criticism, she was ordered by the government to leave The Gambia in 48 hours.<sup>23</sup> Thereafter, the international global health community issued a handful of press releases and then fell into silence, watching as the chaos unfolded and the first cohort of nine HIV-positive people enrolled in PATP, becoming human subjects for the PATP cure.<sup>24</sup>

In the end, the absence of powerful opposition locally and internationally provided the setting

for Jammeh to create and preside over a health dictatorship in a political environment that lacked protection mechanisms for people living with HIV and led unknown numbers to their deaths. Prosper Yao Tsikata, Gloria Nziba Pindi, and Agaptus Anaele state that “the curtailment of individuals' right to make an input into how certain health policies affect their lives, reveals that political dictatorship translates into health dictatorship.”<sup>25</sup> This paper defines health dictatorship as the abuse of power by a political leader or governmental authority that results in undermining patients' autonomy to make informed health decisions based on widely available scientifically sound information and treatment options. Jammeh's health dictatorship through PATP resulted in the violation of patients' right to health and other human rights; flagrant disregard for medical ethics, including a denial of full disclosure and information about the PATP cure; and the undermining of patient autonomy and confidentiality. In addition, Jammeh created a climate of fear that intimidated health care workers and policy personnel working on HIV, thereby affecting the quality of health care services for people living with HIV.

The true impact of the PATP cure on the lives of people living with HIV had not been assessed since Jammeh left the country for self-imposed exile in Equatorial Guinea on January 22, 2017.<sup>26</sup> In 2018, in collaboration with AIDS-Free World, we carried out a mixed-method research study for six weeks to examine the impact of the PATP cure in The Gambia. Our quantitative research surveyed a sample of people living with HIV to determine the impact of PATP on their lives and their health-seeking behavior. The study also examined factors affecting enrollment in PATP. To investigate the program's impact on health service delivery and HIV policy, we conducted qualitative research to elicit the views of individuals working in the HIV policy and the health care sector.

Ethical approval for this research project was provided in the United States by the University of Notre Dame Institutional Review Board and in The Gambia by the Medical Research Council/Gambia Government Joint Ethics Committee.

## Methodology

### Qualitative research

The qualitative research portion of our study examined the impact of the 10-year promotion of PATP on health services for people living with HIV and on HIV policy implementation in The Gambia. We conducted semi-structured in-depth interviews lasting 14–45 minutes each with 15 HIV health care workers and 9 HIV policy implementers. Participants were identified via snowball sampling.

Health care workers participating in the study were required to have worked with people living with HIV before and during PATP so they could discuss changes in health care provision over time. These workers included doctors, nurses, counselors, and community workers. Specific an-

tiretroviral clinics, hospitals, and HIV care centers were identified prior to interviews because not all health facilities provide HIV services. Unfortunately, those who worked directly in PATP declined to participate in the study.

For policy implementers and policy makers, the inclusion criteria were that the person either influenced or was involved in HIV policy creation before and during the implementation of PATP. Through consultation with local partners, we identified the Ministry of Health, World Health Organization, Medical Research Council, the Joint United Nations Programme on HIV/AIDS (UNAIDS), National AIDS Secretariat, National AIDS Control Program, Gambia Network of AIDS Support Societies as key players in HIV policy. We

TABLE 1. Respondents' belief in the ability of the Presidential Alternative Treatment Program to cure HIV

	When you first heard about PATP, did you believe that it had a cure to HIV?		$X^2$	Odds ratio	Significance
	Number of participants responding yes (%)	Number of participants responding no (%)			
Community type			4.26	0.310	0.039
Rural	7 (25.9)	20 (74.1)			
Urban	18 (11.6)	137 (88.4)			
Education level			7.83	0.599	0.018
No formal education	34 (37.0)	58 (63.0)			
Primary	18 (40.9)	26 (59.1)			
Secondary	5 (14.3)	30 (85.7)			
Post-secondary	1 (20.0)	4 (80.0)			
Ethnicity			12.83	N/A	0.012
Mandinka	9 (16.7)	45 (83.3)			
Fula	13 (35.1)	24 (64.9)			
Jola	12 (50.0)	12 (50.0)			
Wolof	21 (43.8)	27 (56.3)			
Other	3 (23.1)	10 (76.9)			

TABLE 2. Respondents' knowledge of PATP and their perceptions of its impacts on people living with HIV

Survey question	Number of participants responding yes (%)	Number of participants responding no (%)	Total
Did public media support PATP?	164 (94.8)	9 (5.2)	173
Did your access to antiretrovirals change while PATP existed?	20 (13.0)	134 (87.0)	154
Do you personally know anyone who participated in PATP?	93 (52.5)	84 (47.5)	177
Do you know anyone who attended PATP and died?	68 (60.2)	45 (39.8)	113
	More discrimination	Less discrimination	No change
How do you think the program affected the amount of discrimination that you experience?	94 (53.1)	33 (18.6)	50 (28.2)

conducted four pilot interviews prior to research implementation to refine the survey tool.

We developed an initial codebook for content analysis, with patterns and themes identified based on open coding.<sup>27</sup> We used both emic and etic analysis. Emic analysis consisted of codes made from participants.<sup>28</sup> For example, during the interviews, the term “defaulters”—meaning people who left conventional HIV care—became a noticed pattern, and we thus used the term as code. Etic analysis—consisting of codes created based on our perspectives as researchers—was used more often.<sup>29</sup> We managed and analyzed the data using a qualitative data analysis program, NVivo Version 11. Links, nodes, and memos were used in the coding process through an examination of transcripts and field notes. We built explanatory themes by sorting and synthesizing the initial codes, categories, and themes. Transcribed interview data and field notes were transferred into PDF formats and uploaded to NVivo for analysis. Coding was stopped when saturation was reached.

### *Quantitative study*

Of the 182 people living with HIV surveyed, 53 were men and 129 were women. The sociodemographic information collected included gender, ethnicity, age, marital status, and education level. We recruited participants from two urban towns (Brikama and Serrekunda) and four rural towns (Sibanor, Bwiam, Soma, and Farfenni). We chose these sites due to their proximity to support societies for people living with HIV. Only four participants were recruited from an antiretroviral treatment site in Brikama to get a subset of people living with HIV who may not be members of an HIV support society. Our inclusion criteria were that the person be over the age of 18 and have been aware of their HIV status during the existence of the program (2007–2016).

We developed a survey and were guided by the Global HIV Strategic Information Working Group, which suggests the inclusion of investigation questions about both demographics and HIV services uptake (access to counseling and testing, knowledge of serostatus, access to care and treatment,

and retention in care).<sup>30</sup> Our survey was divided into five sections: (1) sociodemographic information, (2) health information, (3) general practices relating to HIV, (4) knowledge and perceptions of PATP, and (5) factors involved in PATP enrollment. We used the Likert scale to format the questions and accurately gather information on this complex subject matter (from 1 = “strongly disagree to 5 = “strongly agree”), multiple-choice questions, and open-response questions. Prior to initiating the formal surveys, we conducted pilot surveys to modify the wording of questions and the response structure. Our data excluded participants who had never heard of PATP (n=4) and whose surveys were incomplete (n=1). We administered the survey orally in the major languages spoken in The Gambia: English, Mandinka, Wolof, Jola, and Fula.

Mobile devices utilizing Ona Mobile Data Collection stored responses in the field through Open Data Kit. We analyzed data using the Statistical Packages for the Social Sciences software (version 25.0). Free-response answers were grouped into general themes. We conducted  $X^2$  tests of independence to determine which variables were associated with participants’ perceptions of PATP and their PATP involvement. When analyzing variations between ethnic groups, we grouped Serer, Serahuli, and Others together due to their low response rate.

### Results

Nearly half of the health care workers surveyed (7/15) reported that many of their patients who tried PATP died. Many health care workers (10/15) noticed a decline in patient population because of the PATP cure announcement. Most health care workers (14/15) stated that one impact of PATP was that less funding was available to incentivize staff serving people living with HIV in conventional HIV treatment settings. Health workers’ general belief, though unconfirmed, was that monies for staff serving people living with HIV were being diverted to PATP. Almost half of the health care workers (7/15) reported that coworkers suddenly left their hospital or clinic to work in PATP, where they were paid better salaries.

Most health care workers (11/15) reported feeling uncomfortable telling patients there was no cure for HIV; they feared that this information would get back to Jammeh and they would be punished. A minority of health care workers (3/15) reported actively speaking against the PATP cure to their patients. All nine policy implementers interviewed reported that during PATP's operation, they did not feel safe speaking out against the PATP cure.

For the quantitative portion of our study, we surveyed 182 individuals living with HIV. Of these, 177 had heard about PATP while 5 reported that they had never heard about the program. Among the 177 who were aware of PATP, 168 did not participate in the program and 9 did. The majority of former PATP patients (7/9) strongly disagreed that people joined PATP voluntarily; the remainder (2/9) slightly agreed that participation was voluntary. Similarly, the majority of former enrollees (6/9) strongly disagreed that patients could freely leave PATP if they no longer wanted to participate, and most (5/9) had not felt comfortable asking questions about their treatment. The majority of the 182 individuals surveyed (62.1%) reported first hearing about PATP through the media. Figure 1 shows the methods through which these individuals learned about PATP.

After hearing about PATP for the first time, 61.8% stated that they did not hold PATP in high regard, while 28.3% did. A third of participants (32.7%) initially believed that PATP had a cure for

HIV and 67.2% did not believe that it had a cure. Table 1 summarizes key findings about participants' perceptions on whether PATP had a cure.

More than half of the respondents (53.1%) reported that PATP led to more discrimination against people living with HIV, while 28.2% reported that there was no change in the amount of discrimination they experienced. A staggering 94.8% of all participants surveyed believed that the public media supported PATP. Table 2 shows participants' knowledge of PATP and their perceptions of its impacts on people living with HIV.

The majority of respondents (82.4%) reported that health care workers were their main source of information on HIV. The second most reported source of information was from support groups (14.3%), followed by television and radio (1.1%). Our data analysis found that people living with HIV diagnosed prior to or in 2007, the year when PATP was introduced, were 2.74 times more likely than those diagnosed after 2007 to receive advice not to mix traditional medicine with prescribed treatment ( $RR = 2.74$ , 95% CI [1.02, 7.34]).

Of those surveyed, only nine had been patients at PATP, resulting in low statistical power for generalization among this group. However, these nine individuals provided critical insights concerning PATP's impact on their lives. For example, eight of them did not consider themselves cured of HIV, and four fell sick with other infections while in the program. Our background research found that pa-

TABLE 3. Additional survey responses from former patients in the Presidential Alternative Treatment Program

Survey question	Number (%)
While in the program, could you receive visitors? Yes No	6 (66.7) 3 (33.3)
Did you fall sick with any infections while in the program? Yes No	4 (44.4) 5 (55.6)
Do you feel that your health improved while you were enrolled in PATP? Yes No	5 (55.6) 4 (44.4)
Did you receive reports about the status of your health while you were in the program? Yes No	6 (75.0) 3 (25.0)
Do you consider yourself cured of HIV? Yes No	1 (11.1) 8 (88.9)



tients in PATP were given a bitter herbal concoction that resulted in physical and mental side effects that included constant diarrhea, vomiting, and hallucinations, leaving most in great discomfort for the duration of their stay.<sup>31</sup> Despite the majority (8/9) believing they were not cured by Jammeh's program, five reported feeling that their health had improved during their enrolment in PATP. More than half of them (5/9) did not feel comfortable asking questions about their treatment. Table 3 below shows additional responses about the program given by the nine individuals who had participated in it.

## Discussion

Three former PATP patients have filed a civil suit in the High Court of The Gambia against Jammeh.<sup>32</sup> The suit argues that PATP violated the Gambian Constitution in that patients were subjected to cruel, inhuman, and degrading treatment, and that their confinement in PATP amounted to false imprisonment. The suit also argues that PATP had an adverse impact on the health of these patients.

Indeed, PATP was a major violation of the right to health. The International Covenant on Economic, Social and Cultural Rights provides that everyone has the right "to the enjoyment of the highest attainable standard of physical and mental health."<sup>33</sup> The right to health is defined as including the right to control one's health and body; the right to be free from interference, such as non-consensual medical treatment and experimentation; and "the right to seek, receive and impart information and ideas concerning health issues."<sup>34</sup> With respect to the right to health, states have the responsibility to provide scientifically approved drugs and medically appropriate services that respect confidentiality and medical ethics.<sup>35</sup>

Jammeh's PATP cure disrupted decades of HIV campaign work and "negatively impacted vital HIV services and research partnerships resulting in a significant reduction in competent personnel and services in HIV facilities and suboptimal HIV care with frequent medication stock outs and several patients having their antiretroviral regimens switched often."<sup>36</sup> The program also introduced

policies contrary to The Gambia's national HIV response, resulting in conflicting and confusing messages on HIV management and care.

PATP and the PATP cure flouted Gambian ethical procedures on the development and introduction of new medicines. The PATP cure was given to human subjects without first complying with established national standards for drug testing, contrary to policies of the Ministry of Health and section 9 of the HIV and AIDS Prevention Act (HIV Act).<sup>37</sup> The program strictly forbade people living with HIV from taking their antiretroviral medications, which ran contrary to the government's policy commitment to ensure that all people living with HIV were given antiretroviral treatment, as well as section 10 of the HIV Act (promulgated in 2015, the year prior to Jammeh's electoral defeat), which prohibits spreading false information about HIV and promoting medicines that lack scientifically proven efficacy or that falsely claim to cure HIV.<sup>38</sup> Encouraging people living with HIV to abandon their antiretrovirals endangered public health because of the increased likelihood of the virus spreading within the general population as a result of seropositive people believing they had been cured.

Health care workers and HIV policy implementers reported that PATP created a climate of fear, as Jammeh took extreme action to punish anyone critical of the PATP cure, curtailing the freedom to openly receive and impart information about HIV.<sup>39</sup> Even as late as 2015, the UN Special Rapporteur on torture reported that "a layer of fear ... was visible on the faces and in the voices of many ... from civil society and this even extended to some Government officials."<sup>40</sup> Due to this hostile environment, Gambian HIV experts could not openly challenge or pressure Jammeh to give up the PATP cure—for many, doing so would have resulted in arrest, threats, or even death. The expulsion of senior UN official Gwaradzimba after she publicly criticized the PATP cure had a chilling effect on the community of those working on HIV.<sup>41</sup> As one policy implementer remarked to us during an interview, "After [Gwaradzimba] was expelled, people from other organizations kept their mouths

shut ... They do not want to anger the president and be [exiled], or arrested, or even go missing. You know, because at the time of Jammeh, these things happened constantly. You say something bad about him, and you are done” (interview 22).

This fear among health care workers and policy implementers seriously compromised the quality of HIV-related services, as well as access to information for people living with HIV. Information sharing is critical to the effective management and treatment of HIV, which relies greatly on each patient’s ability to access, understand, and apply health information.<sup>42</sup> Health care workers admitted that they did not dissuade patients from trying the PATP cure and changed the manner in which they counseled people living with HIV. These workers could not openly or fully discuss HIV treatment with their patients. One antiretroviral clinic nurse remarked, “Jammeh had ears everywhere, and if he found out that you were saying bad things about his treatment, you’d get fired or jailed or worse. So even though I knew it was bogus, I did not tell my patients this ... Out of fear!” (interview 15). One nurse who decided to speak against PATP suffered backlash from the Jammeh administration, which threatened to investigate him for suspected wrongdoing in the provision of care for people living with HIV.

In further violation of the free flow of information, the national media was used as a propaganda tool to promote the success of the PATP cure and encourage enrollment. It is likely that after watching, reading, or hearing such propaganda in the media, people living with HIV then sought information from another member of their community to validate what they heard.<sup>43</sup> PATP patients and their testimonials validating the effectiveness of the cure on the national broadcasting station, Gambia Radio Television Services (something that many later asserted was a lie induced by fear), likely also influenced people’s enrollment in the program.<sup>44</sup> Between PATP’s years of operation from 2007 to 2017, while the media promoted the program, conventional health care systems held to the scientifically proven notion that HIV was incurable and that antiretroviral medicines were the only option that could prolong life and manage the disease. This

created a confusing environment with mixed and often conflicting messages on HIV being provided to the public.

Although Jammeh and Gambian experts argued that PATP propaganda had the benefit of reducing the social stigma of being HIV positive, many people living with HIV whom we surveyed reported that they experienced the same or increased levels of discrimination because of the program.<sup>45</sup> Surprisingly, Gambian HIV experts have also argued that one positive impact of PATP was increased uptake of antiretroviral medications.<sup>46</sup> Oddly, Jammeh promoted PATP while also supporting the National AIDS Secretariat, which was responsible for coordinating the efforts of clinics, nonprofits, and other organizations to provide conventional antiretroviral treatment.<sup>47</sup> Fortunately, the majority of survey respondents confirmed that there was no change in access to antiretroviral medications during PATP.

Despite these positive reports of uninterrupted access to antiretroviral treatment, PATP violated international standards on the quality of HIV-related care. According to the World Health Organization, people living with HIV “should be treated with respect with regard to their human rights, ethics, privacy and confidentiality, informed consent, autonomy and dignity.”<sup>48</sup> Furthermore, international guidelines on HIV urge states to take measures to ensure that consumer protection laws and other relevant legislation are “enacted or strengthened to prevent fraudulent claims regarding the safety and efficacy of drugs, vaccines and medical devices, including those relating to HIV.”<sup>49</sup> PATP did not comply with any of these standards, trampling on patient autonomy and confidentiality through its public disclosure of patients’ private health records and resulting in a decline in their already fragile health status by ordering them to stop their antiretroviral medications.<sup>50</sup> The cessation of antiretroviral treatment can lead to serious adverse effects, including death—which sadly occurred in The Gambia. It can also lead to HIV drug resistance.<sup>51</sup>

PATP inflicted cruel, inhuman, and degrading treatment on patients and was an unnecessary medical intervention. Such treatment is prohibited

by various regional and international human rights instruments, including the International Covenant on Civil and Political Rights.<sup>52</sup> As argued by the UN Special Rapporteur on torture, medical care that negligently or intentionally causes severe suffering for no justifiable reason can be considered to constitute cruel, inhuman, or degrading treatment.<sup>53</sup> The poor quality of care in PATP caused physical suffering, with many patients falling sick with opportunistic infections such as tuberculosis.<sup>54</sup> The program's poor-quality care was "both dehumanizing and damaging to their already fragile health status."<sup>55</sup> According to the World Health Organization, health systems providing services to people living with HIV must include the prevention and treatment of opportunistic infections such as tuberculosis and the delivery of antiretroviral medications.<sup>56</sup>

The African Commission on Human and Peoples' Rights has described cruel, inhuman, and degrading treatment as including actions that cause serious psychological suffering and humiliation.<sup>57</sup> PATP's treatment regimen dehumanized people living with HIV by invading their privacy, for it involved sexualized treatment procedures that included touching and massaging private body parts.<sup>58</sup> Jammeh personally slathered and massaged the half-naked bodies of his patients with a mysterious concoction, including over the bare breasts of women living with HIV.<sup>59</sup> The treatment sessions were filmed and subsequently broadcast on the Gambia Radio Television Services, violating patients' confidentiality and disclosure rights. Unauthorized disclosure of HIV status is a frequent abuse against people living with HIV across the globe and can cause severe mental anguish for these individuals.<sup>60</sup>

Former PATP enrollees reported feeling compelled to join the program because of Jammeh's persona as a dictator.<sup>61</sup> Once enrolled, curtailment of their freedom of movement amounted to false imprisonment, with patients reporting that they felt they could not freely leave PATP. Treatment sessions were conducted under the watch of soldiers who also closely guarded and watched patients.<sup>62</sup> Patient autonomy and informed consent were ig-

nored, with patients feeling they could not decline or question treatment procedures.<sup>63</sup>

Moreover, violations continued once patients were discharged from the program. Many of them tried to return to conventional health care to be reinstated on antiretroviral medications but were denied access to services. Such patients thus suffered additional discrimination from health care workers, who labeled them "defaulters" and prioritized patients who had not tried the PATP cure. One health care worker admitted that she stopped accepting patients who had received the PATP cure after 10 of them died in her care in a span of three months.<sup>64</sup>

The international community's response to Jammeh's health dictatorship through PATP was mixed. Some international HIV experts spoke out strongly against Jammeh and PATP. For example, the HIV Medicine Association castigated Jammeh for giving false hope to people living with HIV and for recklessly experimenting with people's lives.<sup>65</sup> Hoosen Coovadia, head of HIV research at the University of KwaZulu-Natal in South Africa, stated, "For a country's leader to come up with such an outlandish conclusion is not only irresponsible, but also very dangerous, and he should be reprimanded and stopped from proclaiming such nonsense."<sup>66</sup>

The World Health Organization and UNAIDS issued a statement that did not directly reprimand PATP or Jammeh's actions, instead reiterating that there was no cure for AIDS and encouraging Jammeh to scientifically examine the safety and efficacy of his treatment.<sup>67</sup> The statement was issued on March 16, 2007, three months after PATP's rollout and roughly a month after Gwaradzimba was expelled from The Gambia. It read in part, "Herbal remedies cannot take the place of comprehensive treatment and care for people living with HIV (including prophylaxis and treatment for opportunistic infections, and highly active antiretroviral therapy where indicated). These treatments should not be stopped in favor of any such remedy."<sup>68</sup> Antonio Filipe Jr., head of the World Health Organization in Senegal, stated, "As the World Health Organization, we would like to state quite clearly the following ... so far there is no cure for AIDS,"

adding that the organization “respects the president’s point of view.”<sup>69</sup> These statements were mild and diplomatic and failed to strongly call out Jammeh’s actions as a violation of the right to health of people living with HIV.

Without strong and persistent opposition, PATP continued for 10 years, and people living with HIV suffered harm while the world—including the UN and World Health Organization—watched. Arguably, the UN’s act of replacing Gwaradzimba (who had openly criticized PATP) and then not placing any further pressure on Jammeh meant that it had resolved to turn a blind eye to the violations being perpetrated on people living with HIV.<sup>70</sup> Even when the Special Rapporteur on torture visited The Gambia in 2015, he did not investigate PATP or the PATP cure—neither was mentioned in his report on human rights issues in the country.<sup>71</sup>

Unfortunately, The Gambia is but one of many instances in which a fraudulent HIV cure or unscientifically sound HIV theory has been promoted by state officials or adopted as official government policy.<sup>72</sup> Historically, the responses of the UN and the World Health Organization have been consistent—diplomatic statements are issued, with no follow-up actions or attempts to protect people living with HIV. When HIV denialism and an attack on access to antiretroviral treatment was spearheaded first by South Africa’s health minister and then by deputy president Thabo Mbeki as an official state policy, the UN merely issued press releases, doing nothing more to counter the propaganda.<sup>73</sup> And in 2007, when Iran announced the immune-modulator drug as an HIV cure and tested it on people living with HIV without their informed consent or an independent ethical review, UNAIDS and the World Health Organization did not even issue a statement.<sup>74</sup> In public remarks, the United Nations Children’s Fund’s coordinator on HIV in Iran at the time said nothing about the drug, instead praising Iran’s efforts to fight HIV.<sup>75</sup>

The UN and World Health Organization must do more to address fraudulent HIV cures beyond issuing press releases and statements. Advocacy campaigns are one option that these organizations have used to address challenges affecting the rights

of people living with HIV. For example, both entities vigorously championed global efforts aimed at ending the criminalization of HIV transmission. To achieve this goal, they generated expert research and guidelines on the harmful impacts of such criminalization and launched and supported a global campaign urging nations to abolish laws that fuel rather than help control and manage HIV.<sup>76</sup> That same vigor should have been used to address the dire situation in The Gambia and should be used now to deal with constantly emerging fraudulent HIV cures that are promoted by powerful political figures or that are part of official state policy.

The World Health Organization has infrastructure and measures in place to deal with counterfeit medicines, but these approaches do not address herbal HIV cures supported by a health dictatorship. Since 1988, it has sought to ensure that governments and pharmaceutical manufacturers cooperate “in the detection and prevention of the increasing incidence of the export or smuggling of falsely labelled, counterfeited or substandard pharmaceutical preparations.”<sup>77</sup> The International Medical Products Anti-Counterfeiting Taskforce (IMPACT) was launched to deal with counterfeit drugs in 2006. IMPACT is made up of national regulators, pharmaceutical companies, nongovernmental organizations, and INTERPOL, among others.<sup>78</sup> Although IMPACT assists states in dealing with counterfeit drugs, it has not designed an approach for dealing with health dictatorships that result in the use of untested herbal medicines or cures.

Similarly, the World Health Organization’s traditional medicine strategy, which seeks to regulate the development of traditional medicines, makes no mention of how to deal with fraudulent traditional medicines promoted from the highest levels of political office.<sup>79</sup> The strategy promises to “facilitate information sharing and international regulatory network development.” An international regulatory framework should address the current gap with respect to health dictatorships.

The Global Surveillance and Monitoring System for Substandard and Falsified Medical Products is an entity of the World Health Organization focused on monitoring and sharing information

on counterfeit medicines and medical products in conventional health settings.<sup>80</sup> It has been publishing reports and issuing drug alerts on counterfeit conventional medicines since 1989 but has never issued a drug alert with respect to PATP or Iran's immune-modulator drug.<sup>81</sup> This is despite the widespread and long-term use of PATP in The Gambia, as well as the reported introduction of the immune-modulator drug beyond Iran's borders into Zimbabwe. In 2013, six years after the drug's rollout in Iran, the Zimbabwean government reportedly added it to the available treatment regimen for HIV positive people in Zimbabwe, despite substandard and unethical testing procedures for the product.<sup>82</sup>

Addressing fraudulent HIV cures globally conforms to UNAIDS' mandate of promoting a human rights-based approach to HIV in order to "create an enabling environment for successful HIV responses and affirm the dignity of people living with, or vulnerable to, HIV."<sup>83</sup> Based on this self-proclaimed goal, UNAIDS needs to work with the World Health Organization to monitor fraudulent HIV cures and their promotion, to develop global standards and guidelines to protect people living with HIV, and to provide advocacy tools for those affected.

## Conclusion

PATP broke Gambian national laws and violated international human rights law by subjecting people living with HIV to cruel, inhuman, and degrading treatment, infringing on their right to health, and flouting international standards of care for people living with HIV. The program also made it difficult for health care workers to effectively deliver health and counseling services to their patients.

The UN and World Health Organization can and should do more to consistently speak out and take action against any purported HIV cures that are distributed to people living with HIV without the backing of rigorous testing procedures that confirm their safety and efficacy. The voice and actions of these international global health actors is necessary to give direction to state policies and protect the human rights of people living with HIV.

Through the Global Surveillance and Monitoring System for Substandard and Falsified Medical Products and IMPACT, the infrastructure and models already exist to monitor and minimize the distribution of conventional counterfeit medicines, and UNAIDS and the World Health Organization should consider adapting these mechanisms to include monitoring fraudulent herbal HIV cures.

Alternatively, UNAIDS and the World Health Organization could consider the creation of a global task force to monitor and provide information on fraudulent cures for HIV and other diseases, including herbal medicines, particularly those that are promoted by governments or political figures. Such an entity could be a global authoritative voice on the efficacy of so-called cures and could work to ensure that governments follow widely accepted protocols in the creation, testing, and rollout of any new drugs in order to avoid causing highly vulnerable people to abandon their life-saving antiretroviral treatments. The task force could also carry out research that measures the impact of fraudulent HIV cures on the fight against HIV and AIDS and documents loss of life due to these harmful initiatives. Currently, deaths resulting from the promotion of fraudulent HIV cures is missing from global statistics on HIV-related deaths. This kind of research is critical for policy formulation at the regional and local levels, as well as for the protection of the rights to life and health of people living with HIV.

Jammeh is not the first head of state to use his power and position to shape access to care and the management of HIV and AIDS, nor will he be the last. According to a Harvard study, former South African president Thabo Mbeki's AIDS denialism in the 1990s caused 300,000 deaths. When people living with HIV and AIDS are victims of state policies that wipe them out by the hundreds and thousands, that is a gross human rights violation. Where fraudulent HIV cures and limited access to antiretroviral medications are championed by those in power, there is a need for enhanced protection of the right to health through international and national protection mechanisms in light of the influence and sway that political leaders have over



citizens. The next fraudulent HIV cure promoted by a powerful individual will certainly come, but is the international global health community ready to stand in defense of people living with HIV?

## References

1. J. Amon, "Dangerous medicines: Unproven AIDS cures and counterfeit antiretroviral drugs," *Globalization and Health* (February 2008). Available at <https://globalizationandhealth.biomedcentral.com/articles/10.1186/1744-8603-4-5>.
2. "Gambia's President claims he has a cure for AIDS," *NBC News* (February 2007). Available at [http://www.nbcnews.com/id/17244005/ns/health-aids/t/gambias-president-claims-he-has-cure-aids/#.W84uY\\_ZFw2w](http://www.nbcnews.com/id/17244005/ns/health-aids/t/gambias-president-claims-he-has-cure-aids/#.W84uY_ZFw2w).
3. Ibid.
4. "Gambia crisis ends as Yahya Jammeh leaves for exile," *Al Jazeera* (January 22, 2017). Available at <https://www.aljazeera.com/news/2017/01/jammeh-arrives-banjul-airport-stepping-170121210246506.html>.
5. Marco Evers, "The quack in Gambia, African despot 'cures' AIDS," (March 8, 2007). Available at <http://www.spiegel.de/international/spiegel/the-quack-in-gambia-african-despot-cures-aids-a-470231.html>.
6. A. Serrano, "Gambia's AIDS 'cure' causes alarm," *CBS News* (2007). Available at <https://www.cbsnews.com/news/gambias-aids-cure-causes-alarm>.
7. "Gambia's President claims he has cure for AIDS" (see note 2).
8. N. M'Bai, *Gambia: The untold dictator Yahya Jammeh's story* (2012).
9. UNAIDS, *Trend of HIV infections* (2018). Available at <http://aidsinfo.unaids.org>.
10. United Nations Population Fund, *The state of world population 2018* (New York: United Nations Population Fund, 2018), p. 149.
11. Amon (see note 1).
12. R. Cassidy and M. Leach, "Science, politics and the presidential AIDS cure," *African Affairs* 108/433 (2009), p. 559.
13. See Presidential Alternative Treatment Program. Available at <http://qanet.gm/statehouse/patp.htm>.
14. C. Petesch, "Gambians file suit against ex-leader over alleged HIV 'cure'" (2018). Available at <https://aidsfreeworld.org/latest-news-1/2018/5/31/ap-gambians-file-suit-against-ex-leader-over-alleged-hiv-cure>.
15. "As Gambia celebrates 'breakthrough in HIV/AIDS cure', dictator Jammeh accuses Western pharmaceutical companies of conspiracy theory!," *Freedom Newspaper* (January 19, 2016). Available at <https://www.freedomnewspaper.com/2016/01/19/6641-2>.
16. Cassidy and Leach (see note 12), p. 559.
17. Ibid., p. 571.
18. M. Darboe, "Playbook of a tyrant," *Torch* (April 4, 2018). Available at <https://torchongambia.wordpress.com/2018/04/04/jammehs-hiv-treatment-was-a-success-drmbowe>.
19. "President's herbal HIV/AIDS 'cure' boosts ARV use," *IRIN* (November 3, 2008). Available at <https://www.irin-news.org/fr/node/243786>.
20. Ibid.
21. R. Becker, "Gambian president's plans for hospital based on bogus claims of AIDS 'cure,'" *Africa Check* (January 29, 2013). Available at <https://africacheck.org/reports/gambian-presidents-plans-for-hospital-based-on-bogus-claims-of-aids-cure>.
22. UN Resident Coordinator's Office, *UN System position with regards to AIDS treatment in The Gambia* (The Gambia: United Nations, 2007), Available at <https://africacheck.org/wp-content/uploads/2013/01/UN-System-Position-with-regards-to-AIDS-Treatment-in-the-Gambia-2007.pdf>.
23. "Gambia expels UN AIDS official for 'cure' criticisms," *Reuters* (February 23, 2007). Available at <https://www.reuters.com/article/us-gambia-aids-un-s/gambia-expels-un-official-for-aids-cure-criticism-idUSL2343601120070223>.
24. Cassidy and Leach (see note 12), p. 560.
25. P. Tsikata, G. Pindi, and A. Anaele, "The frozen rhetoric of AIDS denialism and the flourishing claims of a cure: A Comparative analysis of Thabo Mbeki and Yahya Jammeh's rhetoric," *Communication* 42/3 (2016), pp. 378-397.
26. "Gambia crisis ends as Yahya Jammeh leaves for exile" (see note 4).
27. M. Patton, *Qualitative research and evaluation methods* (Thousand Oaks, CA: Sage Publications, 2015).
28. Ibid.
29. Ibid.
30. Global HIV Strategic Information Working Group, *Biobehavioural survey guidelines for populations at risk for HIV* (2017). Available at <http://apps.who.int/iris/bitstream/10665/258924/1/9789241513012-eng.pdf?ua=1>.
31. C. Freeman, "The president who made people take his bogus HIV cure," *BBC News* (2018). Available at <https://www.bbc.com/news/stories-42754150>.
32. Petesch (see note 14).
33. International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI) (1966), art. 12(1).
34. Committee on Economic, Social and Cultural Rights, *General Comment No. 14, The Right to the Highest Attainable Standard of Health*, UN Doc. E/C.12/2000/4 (2000), para. 8; see also para. 12(b).
35. Ibid, para, 12 (d), (e).
36. G. Ndow, M. Gore, Y. Shimakawa, et al., "Hepatitis B testing and treatment in HIV patients in The Gambia: Compliance with international guidelines and clinical out-

comes," *PLoS One* 12/6 (2017), p. 8.

37. The Gambia Ministry of Health and Social Welfare, *Health policy framework* (January 2006). Available [http://www.ilo.org/wcmsp5/groups/public/---ed\\_protect/---protrav/---ilo\\_aids/documents/legaldocument/wcms\\_126701.pdf](http://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---ilo_aids/documents/legaldocument/wcms_126701.pdf); see also Republic of The Gambia, *HIV and AIDS Prevention and Control Act 2015*.

38. The Gambia Ministry of Health and Social Welfare (see note 37), p. 19; see also Republic of The Gambia, *HIV and AIDS Prevention and Control Act 2015*.

39. Committee on Economic, Social and Cultural Rights (see note 34), para. 12(b).

40. See J. E. Méndez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment: Mission to the Gambia*, UN Doc. A/HRC/28/68/Add.4 (2015).

41. "Gambia's UN envoy 'is expelled,'" *BBC News* (2007). Available at <http://news.bbc.co.uk/2/hi/africa/6390319.stm>.

42. S. Stonbraker, M. Befus, L. Nadal, et al., "Factors associated with health information seeking, processing, and use among HIV positive adults in the Dominican Republic," *AIDS Behavior* 21/6 (2017), pp. 1588-1600.

43. T. Veinot, "Interactive acquisition and sharing: Understanding the dynamics of HIV/AIDS information networks," *Journal of the American Society for Information Science and Technology* 60/11 (2009), pp. 2313-2332.

44. A. Kotze and M. L. Jaiteh, "No sex, no coffee, no ARVs: Former president's quackery could land him in court," *Bhekisisa Center for Health Journalism* (April 24, 2018). Available at <https://bhekisisa.org/article/2018-04-24-00-a-legacy-of-lies-gambians-seek-justice-for-former-presidents-bogus-aids-cure>.

45. "President's herbal HIV/AIDS 'cure' boosts ARV use" (see note 19).

46. *Ibid.*

47. *Ibid.*

48. World Health Organization, *Standards for quality HIV care: A tool for quality assessment, improvement and accreditation* (Geneva: World Health Organization, 2004), p. 8.

49. Office of the United Nations High Commissioner for Human Rights and UNAIDS, *International guidelines on HIV/AIDS and human rights* (Geneva: Office of the United Nations High Commissioner for Human Rights and UNAIDS, 2006), para. 37.

50. See International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI) (1966), art. 12.

51. UNAIDS and World Health Organization, "UN-AIDS and WHO underline importance of evidence based approaches to treatment in response to AIDS," press release (March 16, 2007). Available at [http://www.unaids.org/sites/default/files/web\\_story/070316\\_gambia\\_statement\\_en\\_0.pdf](http://www.unaids.org/sites/default/files/web_story/070316_gambia_statement_en_0.pdf).

52. International Covenant on Civil and Political Rights, G.A. Res. 2200A (XXI) (1966), art. 7.

53. J. E. Méndez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, UN Doc. A/HRC/22/53 (2013), p. 9.

54. "President's herbal HIV/AIDS 'cure' boosts ARV use, IRIN News, November 3, 2008. Available at <https://www.irinnews.org/fr/node/243786>.

55. Méndez (2013, see note 53), p. 17.

56. World Health Organization (2004, see note 48).

57. *Ibid.*

58. "Survivors of Yahya Jammeh's bogus AIDS cure sue former Gambian leader," *Guardian* (June 1, 2018). Available at <https://www.theguardian.com/global-development/2018/jun/01/survivors-yahya-jammehs-bogus-aids-cure-sue-former-gambian-leader>.

59. *The Breakthrough: Part I*. Available at <https://www.youtube.com/watch?v=eADHnTdrMGo>. See also *The Breakthrough: Part II*. Available at <https://www.youtube.com/watch?v=vNPzS2P8MGw>.

60. Méndez (2013, see note 53), p. 17.

61. *Interview Fatou Jatta*. Available at [https://www.youtube.com/watch?v=P\\_gkKa1G69Q&t=20s](https://www.youtube.com/watch?v=P_gkKa1G69Q&t=20s).

62. Kotze and Jaiteh (see note 44).

63. See M. Adeniyi, *Perceptions of the Presidential Alternative Treatment Program among PLHIV in The Gambia*, master's thesis (2018).

64. See J. Ivan, *The effect of the Presidential Alternative Treatment program on health services for PLHIV and HIV policy in The Gambia*, master's thesis (2018).

65. Infectious Diseases Society of America, "HIV experts oppose Gambia's unproven AIDS remedy," *Science Daily* (May 3, 2007). Available at <https://www.sciencedaily.com/releases/2007/04/070430155808.htm>.

66. J. Koinange, "In Gambia, AIDS cure or false hope?," *CNN* (March 17, 2017). Available at <http://edition.cnn.com/2007/WORLD/africa/03/15/koinange.africa>.

67. Amon (see note 1).

68. UNAIDS and World Health Organization (see note 51).

69. Serrano (see note 6).

70. "UNDP names new chief envoy for Gambia after former envoy expelled for questioning President Jammeh's claims of cure for HIV/AIDS," *Kaiser Health News* (2007). Available at <https://khn.org/morning-breakout/drooo44229>.

71. Méndez (see note 40).

72. Amon (see note 1), p. 2.

73. *Ibid.*, p. 4.

74. "Iran introduces new AIDS treatment," *Mehr News* (February 3, 2007). Available at <https://en.mehrnews.com/news/22098/Iran-introduces-new-AIDS-treatment>.

75. Amon (see note 1), p. 3.

76. See UNAIDS, *Ending overly broad criminalization of HIV non-disclosure, exposure and transmission: Critical scientific, medical and legal considerations*. Available at [http://www.unaids.org/sites/default/files/media\\_asset/20130530\\_](http://www.unaids.org/sites/default/files/media_asset/20130530_)

Guidance\_Ending\_Criminalisation\_o.pdf. See also World Health Organization, "Sexual health, human rights and the law." Available at [http://www.who.int/reproductivehealth/publications/sexual\\_health/sexual-health-human-rights-law/en](http://www.who.int/reproductivehealth/publications/sexual_health/sexual-health-human-rights-law/en).

77. World Health Organization, *IMPACT frequently asked questions and answers*, p. 1. Available at <https://www.who.int/medicines/services/counterfeit/impact-faqwa.pdf>.

78. *Ibid.*, p. 3.

79. World Health Organization, *WHO traditional medicine strategy* (2013). Available at [https://www.who.int/medicines/publications/traditional/trm\\_strategy14\\_23/en](https://www.who.int/medicines/publications/traditional/trm_strategy14_23/en).

80. World Health Organization, *WHO global surveillance and monitoring system for substandard and falsified medical products* (2017), p. 5. Available at <https://www.who.int/medicines/regulation/ssffc/publications/gsms-report-sf/en>.

81. World Health Organization, *Full list of WHO medical products alerts*. Available at <https://www.who.int/medicines/publications/drugalerts/en>.

82. T. Ndlovu, "New ARVs deal for Zimbabwe," *Herald* (2013). Available at <https://www.herald.co.zw/new-arvs-deal-for-zim>.

83. UNAIDS, *Human rights*. Available at <http://www.unaids.org/en/topic/rights>.

# Two Row Wampum, Human Rights, and the Elimination of Tuberculosis from High-Incidence Indigenous Communities

RICHARD LONG, COURTNEY HEFFERNAN,\* MELISSA CARDINAL-GRANT, AMBER LYNN, LORI SPARLING, DORILDA PICHE, MARA NOKOHO, AND DIANE JANVIER

## Abstract

The Two Row Wampum belt is a symbolic record of the first agreement between Europeans and American Indians on Turtle Island (North America). The agreement outlined a commitment to friendship and peace between people living perpetually in parallel, with each party recognizing the other as an equal partner. Subsequent treaty relationships between the Indigenous peoples of the Canadian prairies and settler society, along with the colonially imposed structures they spawned, are widely regarded as having broken the Covenant Chain, the foundation of which is Two Row Wampum. For example, the universal right to health, especially public health, as protected by provincial and territorial legislation in Canada, is under threat in Indigenous communities with a high incidence of tuberculosis. The rights of Indigenous peoples have been asserted, and reasserted, in the United Nations Declaration on the Rights of Indigenous Peoples, the Truth and Reconciliation Commission of Canada, the International Patients' Charter for Tuberculosis Care, and Jordan's Principle. Herein we describe the implementation of a strategic plan that reinforces human rights and dignity in the spirit of Two Row Wampum in contemporary tuberculosis elimination efforts.

---

\* *Richard Long and Courtney Heffernan are joint first authors.*

RICHARD LONG is a professor in the Department of Medicine, Faculty of Medicine and Dentistry, and an adjunct professor in the School of Public Health at the University of Alberta, Canada.

COURTNEY HEFFERNAN is a doctoral student in the Department of Medicine, Faculty of Medicine and Dentistry at the University of Alberta, Canada.

MELISSA CARDINAL-GRANT is a research associate at the Tuberculosis Program Evaluation and Research Unit in the Department of Medicine at the University of Alberta, Canada.

AMBER LYNN is a master's student in the School of Public Health at the University of Alberta, Canada.

LORI SPARLING is a health director in a First Nations community in the Province of Saskatchewan, Canada.

DORILDA PICHE is a health educator in a Northern Saskatchewan village with a predominantly Métis population, Canada.

MARA NOKOHO is a former health director in a First Nations community in the Province of Alberta, Canada.

DIANE JANVIER is a health director in a First Nations community in the Province of Alberta, Canada.

Please address correspondence to Richard Long. Email: richard.long@ualberta.ca.

Competing interests: None declared.

Copyright © 2019 Long, Heffernan, Cardinal-Grant, et al. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

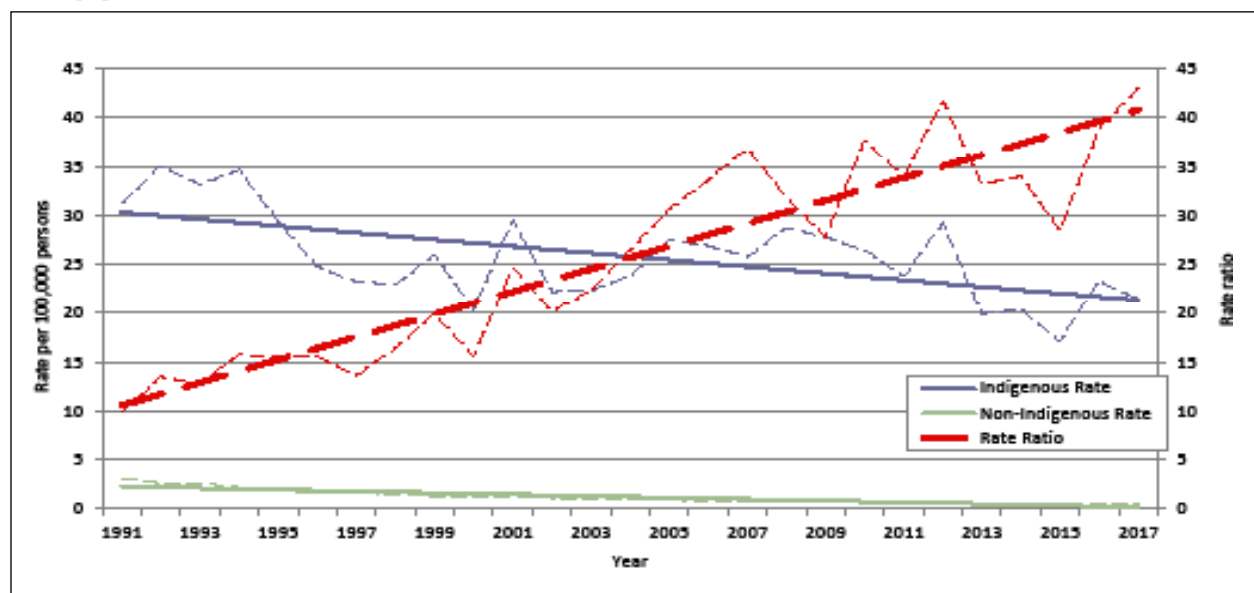
## Introduction

Tuberculosis (TB) is a communicable disease of poverty that exploits conditions of socioeconomic inequity.<sup>1</sup> Every country experiences some inequitable distribution of wealth; national, population-specific measures of TB disease reflect this reality. Disparities in the experience of TB disease are perhaps most stark in high-income countries, where resources are available to effect successful TB prevention and care programs. This is borne out in the literature. TB in India, for example, is five times higher among the poorest quintile than the wealthiest.<sup>2</sup> Meanwhile, in Canada, a high-income, low-incidence country, TB is concentrated in two underserved populations. While the overall rate of TB in Canada is low (4.9 per 100,000 individuals), among foreign-born persons and Indigenous peoples, which include First Nations, Métis and the Inuit (see below), it remains relatively high, at 14.7 and 21.5 per 100,000 individuals, respectively, compared to 0.5 per 100,000 in the Canadian-born non-Indigenous population.<sup>3</sup> This translates into a 29-fold and 43-fold difference in rates, respectively.

Most concerning is that for Indigenous peoples, the relative rate of disease has increased over time. This underscores national TB prevention failures (see Figure 1). If what we call “structural violence” is either that which increases the distance or impedes the decrease of the distance between the potential (the incidence of disease in Canadian-born non-Indigenous populations) and the actual (the incidence of disease in Indigenous populations), then with respect to TB and its causes, an act of violence is being experienced by Indigenous peoples in Canada.<sup>4</sup>

Central to structural violence is the colonization of Indigenous peoples. Writing in the *Lancet*, Malcolm King et al. grouped colonization, globalization, migration, loss of language and culture, and disconnection from the land as Indigenous-specific social inequities, which, along with classic socioeconomic and connectivity deficits, account for disparate health outcomes.<sup>5</sup> Similarly, at the International Symposium on the Social Determinants of Indigenous Health in Adelaide, Australia, in 2007, Indigenous scholar Martin Mowbray opined, “This process [of colonization] continues to impact health and wellbeing and must be remedied if the

FIGURE 1. TB incidence in the Indigenous population of Canada divided by TB incidence in the Canadian-born non-Indigenous population of Canada (1991–2017)



Sources: Public Health Agency of Canada, Tuberculosis in Canada 2001 2007, 2012, 2013 (pre-release), 2014 (pre-release) (Ottawa: Minister of Public Works and Government Services Canada, 2003, 2009, 2015, 2016 (respectively)); J. Vachon, V. Gallant, and W. Siu, “Tuberculosis in Canada, 2016,” Canada Communicable Disease Report 44/3–4 (2018), pp. 78–81; M. Lafreniere, H. Hussain, N. He, and M. McQuire, “Tuberculosis in Canada, 2017,” Canada Communicable Disease Report 45/2–3 (2019), pp. 68–74.



health disadvantages of Indigenous peoples are to be overcome. One requirement for reversing colonization is self-determination, to help restore to Indigenous Peoples control over their lives and destinies.<sup>6</sup> Inter alia, the history of colonization—which in Canada includes the devastating legacy of residential schools—targeted the culture of Indigenous peoples and changed the course of their health for many generations to come.<sup>7</sup>

Colonization is a process whereby a nation in a position of power imposes culture, values, lifestyle, and political structures on those with less power.<sup>8</sup> It has been nearly invariably damaging to the people who experience it, despite motivations that may ostensibly be well intentioned.<sup>9</sup> Relationships between original inhabitants and colonizers have historically manifested in a spectrum of power exchanges that depends on the context of a region. For example, in the plantation settings of the West Indies, such as Haiti, the French, having replaced the Spanish, imposed control of the region through oppression and slavery. Conversely, in regions where colonial settlers had less secure means to subsist, they depended on building relationships with local populations in order to survive.<sup>10</sup> The latter example is evidenced by an agreement reached between the Haudenosaunee of North America and Dutch traders outlining a mutual, three-part commitment to friendship, and peace between peoples, living in parallel forever. Forever is understood to be “as long as the grass is green, as long as the water flows downhill, and as long as the sun rises in the East and sets in the West.” Symbolizing this agreement is a “Two Row Wampum belt.”

Wampum is a mnemonic device—essentially, a cultural archive. Wampum belts recorded important discussions and agreements between nations, especially pertaining to matters of war and peace. Subsequent to agreements, an Indigenous speaker would remind all parties of the expectations of that agreement by reading the Wampum. This occurs when the Wampum commemorating the pact is held up, and the terms of the understanding between the parties that were recorded on the Wampum “document” are reaffirmed.<sup>11</sup> The two rows of the Wampum belt signify Indigenous and

non-Indigenous peoples traveling side by side in harmony and health, with neither having jurisdiction over the other.<sup>12</sup> Two Row Wampum embodies an unchanging relationship between the Haudenosaunee (Iroquois), other Native nations, and their European partners, beginning with the Dutch, then the English, and later Canadians. Despite promotion in the Royal Commission on Aboriginal Peoples, it is not patently obvious that this Two Row Wampum commitment to mutually beneficial relationships has ever been formally practiced.<sup>13</sup>

This paper describes a recent project designed to change the delivery of public health, specifically TB programming, in high-incidence First Nations and Métis communities on the Canadian prairies, through the lens of Two Row Wampum. This project illustrates how relations between Indigenous and non-Indigenous Canadians may be renewed on the basis of the principles of respect and reciprocity in the sphere of health. Strategically, this project has forged a new relationship (or revisits the concept of the Two Row Wampum relationship) between governmental stakeholders and communities. This relationship establishes communities as equal partners in decision making to dismantle, figuratively, the colonially rooted jurisdictional boundaries that separate communities and have heretofore confounded TB control. The principles of Two Row Wampum have application to other communities in Canada with high TB incidence. We posit that a return to Two Row Wampum is not literally decolonizing but shines a light on a path that respects dignity and human rights and has the potential to improve health outcomes in the face of preexistent and persistent colonizing practices by settlers against Indigenous Canadians.

## Background

Complicating the delivery of health services in Canada are the multitude of responsible jurisdictions, which suffer from limited communication and standardization. Under most circumstances, provinces and territories have legislated authority for health, including TB programming, within their borders. Provincial public health legislation

and regulations are “laws of general application” that extend into First Nation reserves. Making this possible is the obligation of First Nations and Inuit Health Branch of Health Canada to provide or make accessible TB services to on-reserve First Nations. Generally, the federal government has a fiduciary responsibility to provide resources and care to reserves and the peoples living therein.<sup>14</sup> In more recent years, resources have been shifting to encourage the autonomy of First Nations to provide their own health services; the most established of these transferred organizations is the First Nations Health Authority of British Columbia.<sup>15</sup> Finally, territories have the sole responsibility for TB prevention and control for their entire populations, though in recent years they have received considerable financial support from Health Canada.<sup>16</sup> Within each province or territory, the provision of TB services is dependent on the priorities, organization, and resources of their governments.<sup>17</sup>

Overlaying the contemporary jurisdictional challenges are invisible and historically fraught relationships between the first peoples of Canada and settler society. These relationships are now legacy. Historian J. R. Miller writes:

*In the latter part of the 1870s, the government of Canada began to reformulate the basis of its policies towards First Nations. Principal in this realignment was the passage by parliament in the spring of 1876 of the Indian Act, a compendium of all legislation dealing with First Nations. The hard centre of the act was casting the relationship of government and Indians as that between trustee and ward. Under the Indian Act First Nations people were legally children, and their legal parent, the federal government, had the right and responsibility to make decisions on their behalf. The trustee-ward/adult-child relationship embodied in the Indian Act is the antithesis of the kin relationship—brother to brother, sister to sister, under their mutual parent, the Great White Queen Mother (the British monarch at the time, Queen Victoria)—agreed to during treaty negotiations.<sup>18</sup>*

The Inuit were never asked to sign a treaty and were never represented under the Indian Act, in spite of a Supreme Court decision in 1939 stating that “Eskimos [Inuit] were Indians” and thus should

be considered wards of the federal government.<sup>19</sup> In 1982, an amendment to the Constitution Act of Canada recognized three major groups of Indigenous peoples: First Nations, who may be registered or unregistered with the federal government under the terms of the Indian Act; Métis, self-identified persons of mixed Indigenous and European ancestry; and Inuit, original inhabitants of the far north who are distinct from other Indigenous groups in heritage, language, and culture. Section 35 of the Canadian Constitution provides recognition and affirmation of Indigenous and treaty rights; it constitutionalized treaties and provided them with immunity against legislatures, as well as enhanced the ability of Inuit and First Nations to advance their rights prior to signing a treaty and protect their interests afterward.<sup>20</sup>

One such interest is comparable health outcomes. TB is a disease of poverty, and elevated rates of TB disease represent an especially evocative disparity between Indigenous and non-Indigenous Canadians, with some First Nations currently experiencing rates of disease rivaling those found in developing nations.<sup>21</sup> In 1992, the Medical Services Branch (the forerunner of the First Nations and Inuit Health Branch of Health Canada) released a National Tuberculosis Elimination Strategy.<sup>22</sup> In 2012, in the face of sustained high rates of TB in First Nations on-reserve, the strategy was renewed in Health Canada’s Strategy against Tuberculosis for First Nations On-Reserve.<sup>23</sup> The renewal was divided into three themes: (1) preventing, diagnosing and managing TB, (2) targeting populations at greatest risk for TB, and (3) developing and maintaining partnerships.

Though the strategy was well intentioned, problems with the themes emerged in the months and years following its release. First, themes one and two were not likely to succeed if theme three failed. Second, on-reserve TB is often linked to off-reserve TB. And third, no steps were taken to see that theme three was implemented, mainly due to a lack of direction. As a way forward, if theme three is about the respectful and meaningful engagement of communities for the purposes of achieving TB elimination, the answer might lie in Two Row Wam-

pum. This arrangement helps bring into the orbit of kin relationship strangers with whom association is desirable. It creates what may be characterized as “imagined communities,” or virtual collectivities fashioned for shared purposes.<sup>24</sup> Moreover, Two Row Wampum helps create an intercultural ethical space that transforms the power dynamic underlying public health. Rather than seeing individuals and communities as passive recipients of government benevolence, it recognizes them as rights holders, with human rights imposing corresponding obligations on governmental duty bearers.<sup>25</sup> An ethical space between the distinctive rows of the Wampum supports the application of rights-based documents to TB prevention and care. Most existing literature recognizes the importance of community engagement on this and other public health issues but provides little instruction as to how that engagement can be meaningful for all parties or how it respects the rights of Indigenous peoples.<sup>26</sup>

Our study explored (1) the development of this aforementioned ethical space, (2) the operationalizing of a human rights-based approach, and (3) a participatory mechanism for working across multiple colonially imposed jurisdictional boundaries. We received funding through a signature Canadian Institutes of Health Research initiative titled “Pathways to Health Equity for Aboriginal Peoples.” In the context of this work, we collaborated with four heterogeneous—with respect to geography, designation, and jurisdiction responsible for delivering health care services—communities. What they share in common are their status as predominantly First Nations and Métis populations and their high rates of TB. These major differences and similarities are important for generalizing any results from participation. All communities are connected with one another historically, linguistically (Dene speakers), economically, and culturally. As a result, their jurisdictional separation, both provincially and on-/off-reserve, constitute potential obstacles to TB control. There is no doubt that progress toward TB elimination is required in all communities to obtain sustained success in any one community. What follows is a reflection on the process of engaging the communities to turn inter-jurisdictional challenges

associated with TB control into an opportunity for advocacy and community-led collaboration.

## Community engagement

Partner communities are located in Northwestern Saskatchewan and Northeastern Alberta (see Figure 2). Each has a sustained high incidence of TB. The weight of ongoing contagion therein was demonstrated by former patients interviewed as part of an earlier study.<sup>27</sup> Against this backdrop, we began a two-phase engagement process consisting of a team-building phase and an implementation science phase.<sup>28</sup>

We built a broad coalition of community, government, First Nations and Métis organizations (tribal councils), and other stakeholders, with the scientific team at the University of Alberta and the University of Saskatchewan acting as brokers. By linking all four communities, this coalition builds on real patterns of human mobility and social relationships rather than a patchwork of externally imposed colonial jurisdictions. Among other people, membership includes the health directors from each of the two reserve communities, the community health education and outreach worker in a predominately Métis community, and the Aboriginal liaison worker in an inner city acting as community co-investigators. Teambuilding began with a face-to-face meeting to reach four goals: (1) determining how decisions would be made within the group, (2) initiating a shared “statement of values” from which all discussion and decision making would proceed, (3) identifying community supports and barriers that have ensured or limited the success of prior TB prevention and care efforts, and (4) discussing “tried and true” interventions for the elimination of TB.

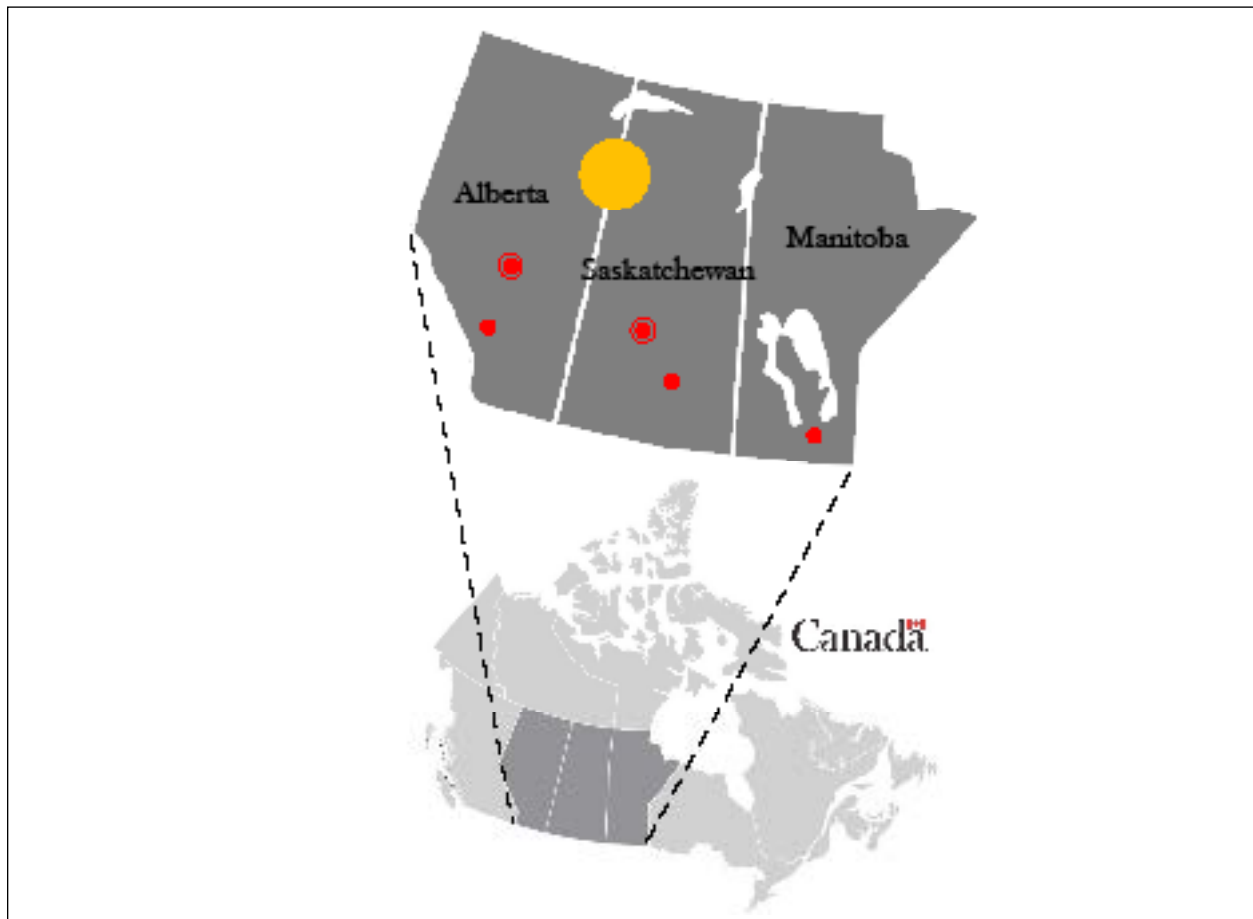
Apropos of the first two goals, we agreed to work together to develop TB programming efforts and interventions with, by, and for Indigenous peoples in their own communities. Decision making within and across communities is by consensus, given the respect accorded to diversity and local autonomy in Indigenous cultures. We routinely speak and share information openly, honestly, and with

respect and dignity; no one member or population group presumes to know what harms or enhances the well-being of others. By unanimous decision, we agreed to respect the rights of Indigenous peoples and the corresponding obligations of governments and other key stakeholders as articulated in the Patients' Charter for Tuberculosis Care, the United Nations Declaration on the Rights of Indigenous Peoples, the Truth and Reconciliation Commission of Canada, and Jordan's Principle (see Table 1), and to use those rights to hold the deliberations and actions of the coalition to account.<sup>29</sup> Present and future assemblage of the coalition occurs within an ethical space, divested of any undercurrent of epistemic racism, where First Nations and Métis collaborators feel safe and free to be themselves. The broad outlines of this space and the narrative

defining the coalition is manifest in the concept of Two Row Wampum (see Figure 3).

Apropos of goals three and four, we identified a need to better resource the communities and create committees to represent local interests. Accordingly, out of partnership funds raised by the scientific team, half-time TB workers were recruited from the communities, and they arranged two committees, one on each side of the provincial border. These committees include community co-investigators, TB workers, Elders, former patients, traditional healers, and students. Their role is indefinite and supported in the future by the communities and governments as appropriate. The fourth goal initiated a conversation about possible interventions for phase two of our study, two of which we implemented after consensus agreement. These two

FIGURE 2. Canada's three Prairie Provinces



Note: The four high-incidence communities are located in an area that spans the border of Northern Alberta and Saskatchewan (see yellow circle). The major metropolitan areas in each province are indicated with red dots; Edmonton and Saskatoon, home to the University of Alberta and the University of Saskatchewan, respectively, are circled.

local-level interventions were (1) region-specific surveillance and translation of those surveillance data back to the community and (2) an expanded program of outreach that has community wellness as its primary focus.

### Surveillance

Up until this point, data has been collected from communities, aggregated, and then used to make decisions centrally at the TB program level. Such aggregate reports obfuscate troubling rates of disease at the community level. Indigenous peoples and communities cannot provide input about solutions they anticipate will be effective if governments and reporting mechanisms serve to maintain ignorance. Our partners want to access data, analyze trends, and advocate for regionally specific strategies against TB. The flow of these data is down. Input about solutions in response to these shared data may spur community-collected and -owned data. Examples include contact tracing successes and failures, barriers to effective case

and contact management (for example, substance misuse), and community-preferred strategies to promote education and reduce stigma. In turn, we anticipate that these locally collected data will be shared with trusted TB stakeholders to ultimately improve TB services. The flow of these data is up.

Surveillance as an elimination strategy has been widely promoted in recently released policy documents and peer-reviewed publications, but the concept of bi-directionality—in other words, sharing data between and across communities and in accordance with an Indigenous ethics code (ownership, control, access and possession, or OCAP)—is unprecedented in Canada.<sup>30</sup> In addition to allowing communities to respond to surveillance data, increasing their ownership of the epidemiologic narrative is a political act.<sup>31</sup> As such, it has the potential to affect not just the delivery of highly specialized services but also the delivery of substantial financial investment in infrastructure and human resources dedicated to community authority and control of health care.

TABLE 1. Human rights, indigenous peoples, and tuberculosis prevention and care

International instruments
<b>World Health Organization Constitution (1946):</b> “The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being,” and governments have the responsibility to ensure “a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity.”
<b>United Nations Declaration on the Rights of Indigenous Peoples (2007), article 23:</b> “Indigenous peoples have the right to determine priorities and strategies for exercising their right to development. In particular, Indigenous peoples have the right to be actively involved in developing and determining health, housing and economic and social programs affecting them and, as far as possible, to administer such program through their own institutions.”
<b>Patients’ Charter for Tuberculosis Care (2006):</b> Tuberculosis patients and their communities have “the right to participate as stakeholders in the development, implementation, monitoring and evaluation of tuberculosis policies and programs with local, national and international authorities.”
National instruments
<b>Truth and Reconciliation Commission of Canada (2015), calls to action #18, 21, 23, 24:</b> “18. We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties.” “21. We call upon the federal government to provide sustainable funding for existing and new Aboriginal healing centres to address the physical, mental, emotional, and spiritual harms caused by residential schools, and to ensure that the funding of healing centres in Nunavut and the Northwest Territories is a priority.” “23. We call upon all levels of government to: <ul style="list-style-type: none"> <li>• Increase the number of Aboriginal professionals working in the health-care field.</li> <li>• Ensure the retention of Aboriginal health-care providers in Aboriginal communities.</li> <li>• Provide cultural competency training for all healthcare professionals.”</li> </ul> “24. We call upon medical and nursing schools in Canada to require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, Treaties and Aboriginal rights, and Indigenous teachings and practices. This will require skills-based training in intercultural competency, conflict resolution, human rights, and anti-racism.”
<b>Jordan’s Principle (2007):</b> A child-first principle intended to “prevent First Nations children from being denied essential public services or experience delays in receiving them” because of jurisdictional disputes over who should cover the cost of care. The principle applies not only to disputes between Canada and a given province or territory but also to disputes between departments within the government.



### Outreach

Rather than focusing narrowly on the diagnosis and treatment of patients with TB who manage to access care on their own, outreach aims to aggressively find all cases of TB, prevent the disease in those populations at highest risk, and attend to populations and places of highest transmission. Further, since local conceptions of wellness tend to be holistic, in the sense that they seek a balance in the health of the mind, body, and spirit with the health of the community and the land, we designed outreach activities in line with this epistemology. A biosocial approach to TB management uniquely tailored to address at-risk populations should take into account cultural nuances and pervasive stigma. Locally delivered outreach is an ideal framework within which a comprehensive strategy for TB elimination can be implemented.<sup>32</sup>

This project and its emphasis on partnership relies on the principle of reciprocal learning to effect change. On the one hand, the education of non-Indigenous stakeholders on the fraught history of colonization and its connection to TB, rights-based documents, and OCAP is necessary. On the other hand, local committees are learning about their rights and the fundamentals of TB prevention

and care. With these tools in hand, we expect that both groups will respect the expertise the other has to offer to achieve the common goal of TB elimination. For example, respect for different worldviews is a sustainable action through the provision and joint interpretation of bidirectional TB surveillance data. Together, team members undertook OCAP training to facilitate the process of data collection and sharing moving forward.

Sustaining the recovery of First Nations and Métis agency within the project and the concept of Two Row Wampum are processes that will eventually fall to programmatic and government stakeholders within the coalition. For example, transforming a system that reinforces social exclusion by marginalizing communities from their data into a system in which communities are fully and centrally involved in decision making will likely not occur within the timelines of a project.<sup>33</sup> Therefore, it is overly ambitious to expect to effect substantial change by research teams alone. Moreover, for the concept of Two Row Wampum to be truly transformative, it would need to be scaled up or rippled out to other high-incidence communities or to all Indigenous communities (see Figures 4 and 5).

FIGURE 3. The allegorical Two Row Wampum Belt, a respectful and meaningful way for high-TB-incidence Indigenous communities and government and programmatic stakeholders to relate to one another



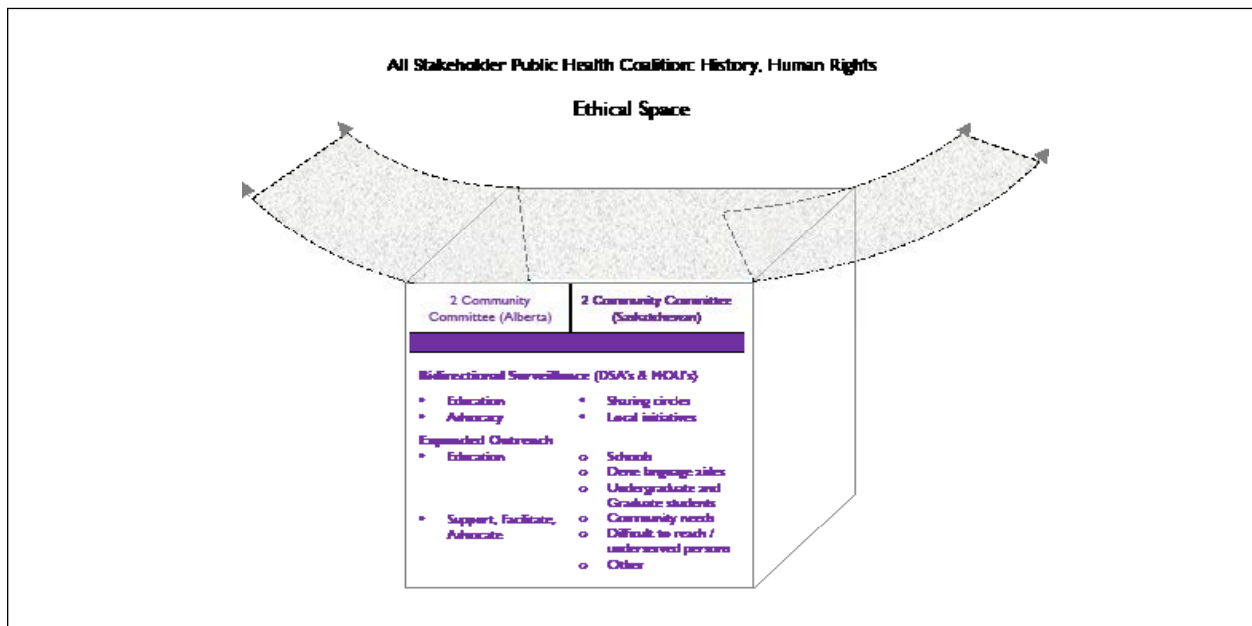
## Discussion

The World Health Organization’s End TB Strategy recognizes the “protection and promotion of human rights, ethics and equity” as one of four principles essential to ending the global TB epidemic, as do we (see Table 2).<sup>34</sup> In 2016, the STOP TB Partnership, the International Human Rights Clinic at the University of Chicago Law School, and the Kenya Legal and Ethical Issues Network on HIV and AIDS developed the Nairobi Strategy: A Human Rights-Based Approach to Tuberculosis.<sup>35</sup> Of the many components of this strategy, the one that overlaps most closely with our project is the component that aims “to formulate and clarify the conceptual, legal, and normative context of a human rights based approach to TB” in a key population group. It relates directly to the Indigenous-specific social inequities that constitute barriers to better TB outcomes, such as the colonially imposed structures that impede the realization of the right to health. Only indirectly does it relate to the usual catalogue of human rights-related barriers to TB services, such as access to care and the stigma and discrimination related to TB in the community. These strategies all have

in common aspirational goals for TB programs, with little direction about how to operationalize rights in their local contexts. We have provided an example herein of how to achieve these goals and why they are critical to TB elimination.

We argue that colonially imposed structural barriers—top-down, paternalistic programming and complex, disconnected jurisdictional systems—serve neither the aspirations of Indigenous peoples for self-expression and self-determination nor the elimination of TB and its upstream determinants. Further, we argue that health, particularly population and public health, of both Indigenous and non-Indigenous peoples, as well as a nation-to-nation vision of relations, requires the creation of an intercultural ethical space where we can achieve parity of thought and power. The structure of this “space” is supported by rights-based approaches to TB programming and care promoted in the Patients’ Charter for Tuberculosis Care, the United Nations Declaration on the Rights of Indigenous Peoples, the calls to action in the Truth and Reconciliation Commission Report, and Jordan’s Principle. We view the space and coalition described herein, as well as the governing processes

FIGURE 4. The ethical space where community priorities are advanced to government and TB program stakeholders



Note: The theoretical space may, ultimately, interface with all high-incidence Indigenous communities in Canada—see dotted lines encompassing a larger space and many more communities. DSA = data sharing agreements; MOU = memorandum of understanding

relating to decision making, as a scalable intervention. Community-specific, local-level interventions are responses to priorities made possible by the advocacy of the coalition and its structure.

In the early twentieth century, savant Albert Schweitzer wrote:

*Colonial problems, as they exist today, cannot be solved by political measures alone. A new element must be introduced; white and coloured must meet in an atmosphere of the ethical spirit. Then only will mutual understanding be possible. To work for the creation of that spirit means helping to make the course of world politics rich in blessings for the future.*<sup>36</sup>

More recently, Indigenous scholar and ethicist Willie Ermine saw an “ethical space” as being formed when two societies with disparate worldviews are poised

to engage each other, each worldview having been molded by a distinct history, knowledge tradition, philosophy, and social and political reality.<sup>37</sup> With respect to population and public health, we see the two (Indigenous and non-Indigenous) as reconciled in such an ethical space.<sup>38</sup> This space requires that equality of nations—rather than the pervasive and often unseen non-Indigenous notions of a monoculture—be respected. The equality and the health of nations was intended in Two Row Wampum, but over time and with the process of colonization, its spirit has been quieted but not forgotten.<sup>39</sup>

These considerations led us to conclude that our research project was as much about the implementation of rights as the implementation of science. Though evidence may support the value of diversity in decision making, the plurality envis-

FIGURE 5. Graphical depiction of a single (panel A) and multiple (panel B) community engagement format

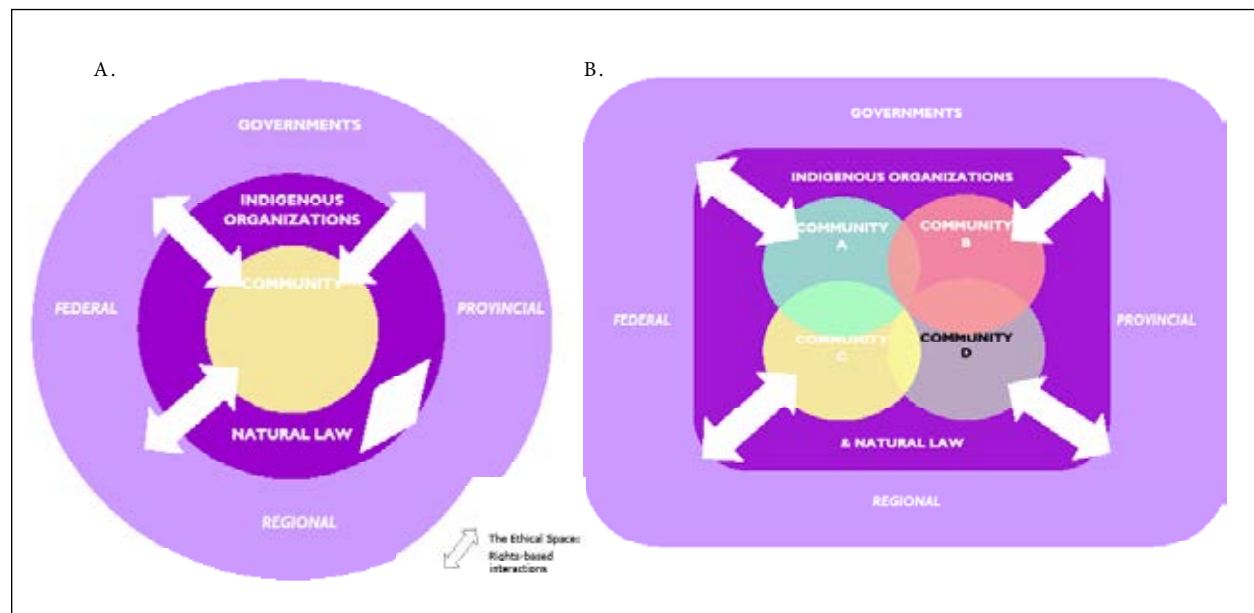


TABLE 2. World Health Organization’s End TB Strategy

Strategy pillars
<ul style="list-style-type: none"> <li>• Integrated patient-centered care and prevention</li> <li>• Bold policies and supportive systems</li> <li>• Intensified research and innovation</li> </ul>
Strategy principles
<ul style="list-style-type: none"> <li>• Government stewardship and accountability, with monitoring and evaluation</li> <li>• Strong coalition with civil society organizations and communities</li> <li>• Protection and promotion of human rights, ethics, and equity</li> <li>• Adaptation of the strategy and targets at country level, with global collaboration</li> </ul>

aged within Two Row Wampum's ethical space is about the right to self-determination, as affirmed and reaffirmed in multiple rights pronouncements. In the words of Indigenous scholar Marlene Brant Castellano, "Fundamental to the exercise of self-determination is the right of peoples to construct knowledge in accordance with self-determined definitions of what is real and what is valuable."<sup>40</sup> One of the local-level interventions chosen by our communities, expanded outreach, reflects the importance of comprehensive kinship obligations. It has precedence in Canada.<sup>41</sup> The other, surveillance as a strategy, has recognized utility elsewhere, but its bi-directionality is unprecedented in Canada. Bi-directional surveillance might more properly be construed as the implementation of an Indigenous right.<sup>42</sup> Given their general application to TB prevention and care, these local-level interventions are also potentially scalable. Our project has called for dialogue and praxis (or the understanding gained through an ongoing cycle of reflection and action) between communities and programmatic and government stakeholders to directly address the question of power and to create a reciprocity in which both parties become "the changer and the changed."<sup>43</sup> As we approach the end of phase two and the need to undertake an evaluation, the scientific team is conscious of the contested power dynamics of the research relationship within a participatory evaluation process.<sup>44</sup>

We conclude that human rights movements, as they relate to public health and communicable disease in Indigenous communities, are complicated by colonially entrenched structural barriers and sociocultural divides that threaten their application.<sup>45</sup> In Canada, this is so despite universal health care and a consistently high ranking in the United Nations Development Programme's Human Development Index.<sup>46</sup> Clearly, the politics of assimilation—relentlessly pursued in Canada through discriminatory practices, treaties, and the residential school system—has failed. Perhaps it is failing globally as the industrial mindset (only a few centuries old) proceeds apace at the expense of respect for the universe, the interconnectedness of all living things, and the virtue of being—In-

igenous concepts developed by rich and diverse cultures over many millennia. Herein we affirm the existence of two objectivities, each claiming its own distinct and autonomous worldview. For the health of nations and the elimination of biosocial diseases, we propose the co-creation of an ethical space for dialogue, its placement within the concept of Two Row Wampum, and its linkage to human rights law. Human rights, now so clearly enunciated, are critical to ending structural violence and placing members of both nations on a better path.

## Acknowledgment

The authors are very grateful to all of the members of the coalition for the many contributions to the success of this project and to the funding agencies (Canadian Institutes of Health Research, Saskatchewan Health Research Foundation, Alberta Innovates Health Solutions, and the First Nations and Inuit Health Branch, Alberta and Saskatchewan Region) for their generous support.

## Funding

Canadian Institutes of Health Research (Grant numbers RN246253-337694 and RN298107-379492), Saskatchewan Health Research Foundation, and Alberta Innovates Health Solutions.

## References

1. K. Lönnroth, E. Jaramillo, B. G. Williams, et al., "Drivers of tuberculosis epidemics: The role of risk factors and social determinants," *Social Science and Medicine* 68 (2009), pp. 2240–2246.
2. O. Oxlade and M. Murray, "Tuberculosis and poverty: Why are the poor at greater risk in India?" *PLoS ONE* 7/11 (2012), p.e47533.
3. M. Lafreniere, H. Hussain, N. He, and M. McQuire, "Tuberculosis in Canada, 2017," *Canada Communicable Disease Report* 45/2–3 (2019), pp. 68–74.
4. J. Galtung, "Violence, peace and peace research," *Journal of Peace Research* 6 (1969), pp. 168–191; S. Patel, C. Paulsen, C. Heffernan, et al., "Tuberculosis transmission in the Indigenous peoples of the Canadian Prairies," *PLoS One* 12/11 (2017), p. e0188189; P. E. Farmer, B. Nizeye, S. Stulac, and S. Keshavjee, "Structural violence and clinical medicine," *PLoS Medicine* 3/10 (2006), p. e449.



5. M. King, A. Smith, and M. Gracey, "Indigenous health part 2: The underlying causes of the health gap," *Lancet* 374 (2009), pp. 76–85.
6. Commission on Social Determinants of Health, *Social determinants and indigenous health: The international experience and its policy implications; Report on specially prepared documents, presentations and discussion at the international symposium on the social determinants of Indigenous health Adelaide, 29–30 April 2007* (Adelaide: Finders University, 2007).
7. F. J. P. Hackett, S. Abonyi, and R. F. Dyck, "Anthropometric indices of First Nations children and youth on first entry to Manitoba/Saskatchewan residential schools—1919 to 1953," *International Journal of Circumpolar Health* 75/1 (2016); J. S. Milloy, *A national crime: The Canadian government and the residential school system, 1879 to 1986* (Winnipeg: University of Manitoba Press, 1999).
8. E. I. Daes, "Prologue: The experience of colonization around the world," in M. A. Battiste (ed), *Reclaiming indigenous voice and vision* (Vancouver: UBC Press, 2000), pp. 3–8; J. S. Youngblood Henderson, "The context of the state of nature," in M. A. Battiste (ed), *Reclaiming Indigenous voice and vision* (Vancouver: UBC Press, 2000), pp. 11–38.
9. Youngblood Henderson (see note 8).
10. A. M. Carlos and D. L. Frank, *Commerce by a frozen sea: Native Americans and the European fur trade* (Philadelphia: University of Pennsylvania Press, 2010).
11. J. R. Miller, *Compact, contract, covenant: Aboriginal treaty-making in Canada* (Toronto: University of Toronto Press, 2009).
12. J. Parmenter, "The meaning of kaswentha and the two row Wampum belt in Haudenosaunee (Iroquois) history: Can Indigenous oral tradition be reconciled with the documentary record?" *Journal of Early American History* 3 (2013), pp. 82–109; Chief I. Powless Jr., "Treaty making," in G. P. Jemison and A. M. Schein (eds), *Treaty of Canandagua 1794–200: Years of treaty relations between the Iroquois confederacy and the United States* (Santa Fe: Clear Light Publishers, 2003), pp. 15–34.
13. Royal Commission on Aboriginal Peoples, *Report of the royal commission on Aboriginal peoples* (Ottawa: Canada Communication Group – Publishing, 1996). Available at <http://www.bac-lac.gc.ca/eng/discover/aboriginal-heritage/royal-commission-aboriginal-peoples/Pages/final-report.aspx>.
14. Pan-Canadian Public Health Network, *Guidance for tuberculosis prevention and control programs in Canada* (Ottawa: Public Health Agency of Canada, 2012). Available at <http://www.phn-rsp.ca/pubs/gtbpccp-oppctbc/pdf/Guidance-for-Tuberculosis-Prevention-eng.pdf>.
15. Tuberculosis Services, *Community programming guide: First Nations Health Authority*. Available at [www.fnha.ca](http://www.fnha.ca).
16. Inuit Tapiriit Kanatami, *Inuit tuberculosis elimination framework* (Ottawa: Inuit Tapiriit Kanatami, 2018). Available at <https://www.itk.ca/wp-content/uploads/2018/12/FINAL-ElectronicEN-Inuit-TB-Elimination-Framework.pdf>.
17. National Collaborating Centre for Aboriginal Health, *The state of knowledge of Aboriginal health: A review of public health in Canada*. Available at <https://www.ccsa-nccah.ca/docs/context/RPT-StateKnowledgeReview-EN.pdf>.
18. Miller (see note 11).
19. *Reference as to whether "Indians" includes in s. 91 (24) of the B.N.A. Act includes Eskimo in habitants of the Province of Quebec* (1939), S.C.R. 104 (1939 CanLII 22 (SCC)).
20. *The Constitution Act, 1982, Schedule B to the Canada Act 1982 (UK)* (1982), c 11.
21. R. Long, V. Hoepfner, P. Orr, et al., "Marked disparity in the epidemiology of tuberculosis among Aboriginal peoples on the Canadian Prairies: The challenges and opportunities," *Canadian Respiratory Journal* 20 (2013), pp. 223–230.
22. Medical Services Branch Working Group on Tuberculosis, *National tuberculosis elimination strategy* (Ottawa: Medical Services Branch, 1992).
23. Health Canada, *Health Canada's strategy against tuberculosis for First Nations on-reserve* (Ottawa: Health Canada, 2012). Available at [http://publications.gc.ca/collections/collection\\_2012/sc-hc/H34-245-2012-eng.pdf](http://publications.gc.ca/collections/collection_2012/sc-hc/H34-245-2012-eng.pdf).
24. Miller (see note 11).
25. B. M. Meier, D. P. Evans, M. M. Kavanagh, et al., "Human rights in public health: Deepening engagement at a critical time," *Health and Human Rights Journal* 20 (2018), pp. 85–91.
26. D. Wilson, S. de la Ronde, S. Brascoupé, et al., "Health professionals working with First Nations, Inuit, and Metis consensus guidelines," *Journal of Obstetrics and Gynaecology Canada* 35 (2013), pp. 550–558; A. Sisco, "Honoring the katswenta (two row Wampum): A Framework for consultation with Indigenous communities in Canada and Australia," doctor of philosophy thesis, School of Education, Faculty of Social Sciences, University of Wollongong (2015). Available at <https://ro.uow.edu.au/theses/4345>; N. Romero-Sandoval, O. Flores-Carrera, M. A. Molina, et al., "DOTS strategy and community participation: An experience in the Ecuadorian Andes," *International Journal of Tuberculosis and Lung Disease* 13 (2009), pp. 1569–1571; E. George, T. Mackean, F. Braun, and M. Fisher, "Social determinants of Indigenous health and Indigenous rights in policy: A scoping review and analysis of problem representation," *International Indigenous Policy Journal* 10 (2019).
27. J. Boffa, M. King, K. McMullin, and R. Long, "A process for the inclusion of Aboriginal people in health research: Lessons from the determinants of TB transmission project," *Social Science and Medicine* 72 (2011), pp. 733–738; K. McMullin, S. Abonyi, M. Mayan, et al., "Evoking 'Old Keyam' as a response to the disproportionate experience of tuberculosis among Aboriginal peoples of the Canadian



- Prairies,” *Journal of Aboriginal Health* 9 (2012), pp. 30–40; S. Abonyi, M. Mayan, K. McMullin, et al., “Finally when I started falling down: Indigenous tuberculosis patient experiences of health and illness on the Canadian Prairies,” *International Journal of Indigenous Health* 11/2 (2017), pp. 3–23; S. Komarnisky, P. Hackett, C. Heffernan, et al., “Years Ago: Reconciliation and First Nations narratives of tuberculosis in the Canadian Prairie Provinces,” *Critical Public Health* 26/4 (2016), pp. 381–393; M. Mayan, T. Robinson, R. Gokiart, et al., “Respiratory isolation for tuberculosis: The experience of Indigenous peoples on the Canadian Prairies,” *Public Health Action* 7/4 (2017), pp. 275–281; M. Mayan, R. Gokiart, T. Robinson, et al., “Community setting as a determinant of health for Indigenous peoples living in the Prairie Provinces of Canada: High rates and advanced presentations of tuberculosis,” *International Indigenous Policy Journal International Indigenous Policy Journal* 10 (2019).
28. S. Theobald, N. Brandes, M. Gyapong, et al., “Implementation research: New imperatives and opportunities in global health,” *Lancet* 392 (2018), pp. 2214–2228.
29. K. Arunagiri, *The patients’ charter for tuberculosis care: Patient rights and responsibilities* (World Care Council, 2006); United Nations Declaration on the Rights of Indigenous Peoples, G.A. Res. 61/295 (2007); Truth and Reconciliation Commission of Canada, *Honouring the truth, reconciling for the future: Summary of the final report of the truth and reconciliation commission of Canada* (Ottawa: Truth and Reconciliation Commission of Canada, 2015); Government of Canada, *Jordan’s Principle* (Ottawa: House of Commons, 2007); World Health Organization, *Constitution of the World Health Organization* (New York: World Health Organization, 1946).
30. G. Theron, H. E. Jenkins, F. Cobelens, et al., “Data for action: Collection and use of local data to end tuberculosis,” *Lancet* 386 (2015), pp. 2324–2333; K. Lönnroth, G. B. Migliori, I. Abubakar, et al., “Towards tuberculosis elimination: An action framework for low incidence countries,” *European Respiratory Journal* 45 (2015), pp. 928–952; Health Canada, *Summary: Monitoring and performance framework for tuberculosis programs for First Nations on-reserve*. Available at <https://www.canada.ca/en/health-canada/services/publications/science-research-data/monitoring-performance-framework-tuberculosis-programs-first-nations-reserve-2015.html>; B. Schnarch, “Ownership, control, access, and possession (OCAP) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities,” *International Journal of Aboriginal Health* 1 (2004), pp. 80–95.
31. J. O’Neil, J. Reading, and A. Leader, “Changing the relations of surveillance: The development of a discourse of resistance in Aboriginal epidemiology,” *Human Organization* 57 (1998), pp. 230–237.
32. K. F. Ortblad, J. A. Salomon, T. Bärnighausen, and R. Atun, “Stopping tuberculosis: A biosocial model for sustainable development,” *Lancet* 386 (2015), pp. 2354–2362.
33. J. Smylie, A. Lofters, M. Firestone, and P. O’Campo, “Population-based data and community empowerment,” in P. O’Campo and J. R. Dunn (eds), *Rethinking social epidemiology: Towards a science of change* (Dordrecht: Springer, 2012), pp. 67–92.
34. World Health Organization, *The end TB strategy* (Geneva: World Health Organization, 2015).
35. Stop TB Partnership, Kenya Legal and Ethical Issues Network on HIV and AIDS, and University of Chicago School of Law, *The Nairobi strategy: A human rights-based approach to tuberculosis* (Geneva: Stop TB Partnership, 2016).
36. A. Schweitzer, *Out of my life and thought* (New York: The New American Library of World Literature, 1959).
37. W. Ermine, “The Ethical space of engagement,” *Indigenous Law Journal* 6 (2007), pp. 193–203.
38. P. McIntosh, “White privilege: Unpacking the invisible knapsack,” in S. Rothernburg (ed), *Race, class and gender in the United States: An integrated study* (New York: St Martin’s Press, 1998), pp. 165–168.
39. Royal Commission on Aboriginal Peoples (see note 13).
40. M. B. Castellano, “Ethics of aboriginal research,” *Journal of Aboriginal Health* 1 (2004), pp. 98–114.
41. G. G. Alvarez, D. D. VanDyk, S. D. Aaron, et al., “TAI-MA (Stop) TB: The impact of a multifaceted TB awareness and door-to-door campaign in residential areas of high risk for TB in Iqaluit, Nunavut,” *PLoS ONE* 9/7 (2014), p. e100975.
42. J. Smylie, I. Anderson, M. Ratima, et al., “Indigenous health performance measurement systems in Canada, Australia, and New Zealand,” *Lancet* 367 (2006), pp. 2029–2031.
43. N. Wallerstein, “Power between evaluator and community: Research relationships within New Mexico’s healthier communities,” *Social Science and Medicine* 49/1 (1999), pp. 39–53.
44. *Ibid.*, p. 49.
45. B. Citro, E. Lyon, M. Mankad, et al., “Developing a human rights-based approach to tuberculosis,” *Health and Human Rights Journal* 18 (2016), pp. 1–8; C. Gianella, C. Ugarte-Gil, G. Caro, et al., “TB in vulnerable populations: The case of an Indigenous community in the Peruvian Amazon,” *Health and Human Rights Journal* 18 (2016), pp. 55–68.
46. United Nations Development Programme, *Human development indices and indicators: 2018 statistical update* (New York: United Nations Development Programme, 2018).



## RESEARCH PROTOCOL

## Assessing a Human Rights-Based Approach to HIV in Kenya

NEILOY R. SIRCAR, TABITHA G. SAOYO, AND ALLAN A. MALECHE

## Abstract

Kenya is actively encouraging HIV testing and notification services in order to identify persons living with HIV and link them to treatment. Recently, Kenya and international supporters of its HIV program have sought to scale up these services through increased capacity and training. However, little is known about how this strategy has been implemented and is being sustained, particularly regarding the human rights of persons living with or at risk for HIV. This exploratory qualitative study seeks perspectives from health providers and populations at risk for HIV, including young women, men who have sex with men, sex workers, and injection drug users. Our primary data collection methods will be focus group discussions and in-depth interviews. We will transcribe and analyze data under a grounded theory approach to compare outputs from populations at risk for HIV with outputs from health providers. We will also apply a rights analysis to the data's codes and themes to assess how effectively Kenya's HIV strategy, policies, and practices adhere to a human rights-based approach. The results will support both rights realization among at-risk populations and the public health objectives for HIV testing and treatment.

---

NEILOY R. SIRCAR is a 2018–2019 NIH/Fogarty-Northern Pacific Global Health Fellow and a 2018–2019 Afya Bora Fellow, University of Washington, USA.

TABITHA G. SAOYO is deputy director of the Kenya Legal and Ethical Issues Network, Nairobi, Kenya.

ALLAN A. MALECHE is executive director of the Kenya Legal and Ethical Issues Network, Nairobi, Kenya.

Please address correspondence to Neiloy R. Sircar. Email: nsircar@uw.edu.

Competing interests: None declared.

Copyright © 2019 Sircar, Saoyo, and Maleche. This is an open access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted noncommercial use, distribution, and reproduction in any medium, provided the original author and source are credited.

## Introduction

HIV is a tragic health and human rights concern made all the more problematic where the human rights of those persons at risk for HIV or living with HIV are compromised in the pursuit of a public health strategy. Violations of individual consent, privacy, and confidentiality are rarely justifiable, even when the goal is to promote access to treatment and care.

Kenya has enacted policies and encouraged practices that support human rights for persons who are at risk for HIV or living with HIV. However, the communities at risk for HIV do not always experience the best practices for the protection of their rights or know that there are laws and policies that protect them. Further, historical discrimination against communities at risk for HIV—due to sexual orientation, gender, work, and habits and lifestyle—can color individual and community perceptions of health services even before any interactions.

To address these concerns, Kenya has adopted laws, practices, and statements affirming a human rights-based approach to HIV that rests on a public health strategy that protects, respects, promotes, and fulfills the human rights of all persons at risk for HIV or living with HIV.

Beyond affirmations alone, the implementation of a rights-based approach—as reflected in the perceptions, policies, and practices of health care professionals and validated in the perceptions and experiences of those individuals at risk for HIV who access the Kenyan health care system—provides an opportunity for research into how public health programs can be evaluated and analyzed utilizing a rights-oriented framework. Public health programming may better achieve its objectives through complementary, tangible rights-realizing interventions. Research that assesses the efficacy of public health policies and practices in respecting, protecting, promoting, and fulfilling human rights will support fidelity to a human rights-based approach.

## Background

Kenya's HIV epidemic disproportionately affects

vulnerable communities, including young women and persons from key populations, such as sex workers, men who have sex with men, and people who inject drugs.<sup>1</sup> We refer to these groups collectively as “key and affected populations.” As a result, the Kenyan National AIDS and STI Control Programme (NAS COP), the Ministry of Health, and other Kenyan public health authorities (as well as international supporters such as the US President's Emergency Plan for AIDS Relief, or PEPFAR) have been scaling up their HIV testing strategies to increase testing rates and to widely implement notification services, chiefly assisted partner notification services, to connect at-risk persons to HIV testing services.

As outlined in NAS COP's 2015 National HIV Testing Services Guidelines, Kenya employs several approaches to HIV testing in order to facilitate access to HIV services, testing, and treatment in a variety of conditions.<sup>2</sup> These include facility-based and community-based settings that offer both client-initiated and provider-initiated testing and counseling. In addition, assisted partner notification services have been particularly effective in identifying persons for outreach and testing, utilizing an index case (a person living with HIV) to identify other parties—usually partners, though children as well—to simplify case finding.

It is estimated that half of all people living with HIV in Kenya are unaware of their HIV status.<sup>3</sup> Overall, testing for HIV is improving, yet testing rates among key populations and young women remain stubbornly low: while 80–90% of female sex workers in Kenya report having tested for HIV within the past 12 months, only 77% of men who have sex with men, 84% of people who inject drugs, and 53% of women aged 15–24 report having done so.<sup>4</sup> These rates represent significant improvements since 2011 (for example, in 2011, a mere 29.2% of women aged 15–24 had tested for HIV within 12 months of being asked, as well as just 35.5% of men who have sex with men), which makes it all the more important to sustain this momentum in testing and to do so in a manner that is respectful of the rights and dignity of persons at risk for and living with HIV.<sup>5</sup>

### *HIV and risks to patients' rights*

HIV testing strategies have been increasingly looking to high-yield methods for identifying persons at risk for HIV and facilitating their access to care. Partner notification services and similar approaches have been shown to be effective at identifying persons within the immediate orbit of an index case.<sup>6</sup> Nevertheless, some communities at risk for HIV or living with HIV have concerns about disclosure, particularly its potential to increase stigma, discrimination, abandonment, and intimate partner violence and other forms of violence.<sup>7</sup> These feelings inhibit positive perceptions of HIV testing services and assisted partner notification services, and they reflect people's conceptions concerning their human rights and how those rights are regarded when being tested for HIV or being asked to disclose a positive status to others.<sup>8</sup>

Coercive HIV testing, as well as coercive notification of a partner or other person about one's status, is a gross violation of human rights that nevertheless has been widely experienced within at-risk communities. In 2013, Eileen Moyer et al. noted that the non-consensual disclosure of a person's HIV status in Kenya was commonplace and that some people had been coerced into testing, which affected community perspectives on HIV testing and on health services generally.<sup>9</sup> Even where coercion was not overt (such as a threat or an unlawful requirement to test for HIV before receiving other services), constructively coercive environments—such as clinical settings where patients could not enjoy privacy or confidentiality—were found to unduly affect individuals' autonomy.

### *HIV and a human rights-based approach to improving public health*

A human rights-based approach to HIV testing and disclosure places the rights of people being tested at the center of all services. Kenyan health authorities and supporters such as PEPFAR concur that rights-based approaches need to form the basis of training for health service providers, especially for “[key population] friendly services.”<sup>10</sup> The human rights of persons at risk of and living with HIV and AIDS include their rights to dignity,

respect, privacy, and confidentiality, as well as the right to provide informed consent and to refuse consent.<sup>11</sup> Training health service providers in the adoption of a rights-based approach necessitates sensitivity, recognition, and familiarity with the concerns of key populations. Further, accomplishing and cementing such training requires a strong legal and policy framework under which health care professionals can work. HIV testing must be voluntarily consented to, and the patient must be fully informed (for example, by receiving adequate pre-counseling) and their information kept private and confidential. Kenya's 2010 Constitution and its 2006 HIV and AIDS Prevention and Control Act afford the right to—and expectation of—privacy and confidentiality, in accordance to international law and norms including those adopted by the East African Community (of which Kenya is a member).<sup>12</sup> Kenyan health authorities and providers are thereby obligated to ensure that all Kenyans enjoy their rights consistently and uniformly whenever and wherever they interact with the health care system.<sup>13</sup>

Yet, at the time of writing, neither NASCOP's guidelines on assisted partner notification services nor the required privacy regulations under the 2006 HIV and AIDS Prevention and Control Act had been adopted by Kenyan authorities. The degree to which rights-related training has been integrated into health care worker education in Kenya is unclear, as is the extent to which policies and practices on patients' rights are upheld in a uniform and consistent manner.

### Research rationale

We believe that an evaluation of how a rights-based approach is implemented is vital to identifying, and improving on, effective and rights-enabling components of Kenya's HIV strategy. In addition, we intend to demonstrate the utility of a human rights-oriented analysis for public health programming (in other words, we seek to evaluate the “approach” in “human rights-based approach” to HIV). Given concerns of abuse, stigma, discrimination, and other negative consequences among



the key populations and vulnerable groups at risk for HIV, Kenyan HIV policies and practices should reflect on and be informed by studies showing implementation gaps with respect to human rights.<sup>14</sup> Our study and its results will aid public health policy planners and health providers in their engagement with at-risk communities and so contribute to building trust and confidence among key stakeholders in Kenya's HIV and human rights context.

## Research objectives

### *General objective*

This research asks how normative statements in law and policy documents become embedded (or not) in health care workers' practices and patients' experiences. The study collects opinions, feelings, and perspectives from both the HIV at-risk communities generally targeted by Kenyan and international public health actors and the Kenyan public health and health care workers who design and implement HIV testing and notification strategies. This data will help us understand how, and to what degree, Kenyan HIV testing and notification policies and practices are rights realizing with respect to key and affected populations, particularly concerning their rights to consent, privacy, and confidentiality.

### *Specific objectives*

Our study contains three specific objectives, refined through peer review with our respective institutional review boards at Georgetown University and Kenya Medical Research Institute.

1. Document opinions, concerns, attitudes, and perspectives (both positive and negative) within at-risk communities related to testing for HIV and disclosing HIV status, and connect those concerns to recognized human rights in Kenya.
  - a. Sub-objective: Assess at-risk communities' level of awareness of their human rights under Kenyan and international law as they relate to HIV testing and notification services.
  - b. Sub-objective: Gauge key and affected pop-

ulations' level of trust and confidence in the health system with regard to their legal rights.

Approach: Focus group discussions and in-depth interviews with key and affected populations.

2. Document providers' and health professionals' perspectives on HIV testing and disclosure practices regarding at-risk communities, including opinions on training programs for health care workers that relate to key and affected populations' sensitization and patients' rights.

a. Sub-objective: Assess rights awareness and attitudes toward balancing human rights for persons at risk for or living with HIV with public health imperatives to identify and link at-risk persons to testing and treatment services.

Approach: Key informant in-depth interviews with HIV health care providers and professionals (nurses, counselors, doctors, and policy experts).

3. Explore whether and where human rights interventions—including reforms in policy, law, training, and practice—might contribute to rights realization and increased health care utilization among HIV at-risk communities.

Approach: Legal analysis relating Kenyan and international human rights law to the emergent codes and themes from our qualitative analysis (our "facts," if anecdotal), and concluding how well the human rights-based approach in Kenya is being implemented procedurally and substantively.

## Design and methodology

### *Setting*

Kenya's legal and policy framework is supportive of human rights in health, including for key and affected populations who bear the brunt of stigmatizing exclusion, and guidelines around privacy, confidentiality, and consent are extolled within HIV public health programs. As a result, Kenya presents a strong foundation to conduct a legal analysis for the implementation of an HIV public health strate-

gy that adheres to a human rights framework.

Taking into account prevailing key and affected population demographics and high HIV prevalence, we selected four study sites to conduct our discussions: Nairobi County (high concentration of men who have sex with men), Kisumu County (high concentration of sex workers), Homa Bay County (high population of young women), and Mombasa County (high concentration of people who inject drugs).

### *Sample size*

Our total sample size is expected to be 50 persons: 36 focus group discussion participants and 14 in-depth interview participants.

### *Inclusion criteria*

- Self-identification with one of our target populations (men who have sex with men, people who inject drugs, young women aged 18–24, sex workers, and health care providers or professionals).

### *Exclusion criteria*

- Participant not independently capable of consenting to participate.
- Participant not willing to participate primarily in English or Swahili.
- Focus group: participant already taking part in an in-depth interview.
- In-depth interview: participant already taking part in a focus group.

### *Recruitment*

Our study benefitted from established relationships between our organization, Kenya Legal and Ethical Issues Network, and members of Kenyan civil society. Community-based organizations and civil society organizations supported participant mobilization by circulating invitations to participate in our study to members and affiliates. We instructed these partners that all participation must be voluntary and unrelated to a participant's role in their respective organization (for example, the focus group discussions and in-depth interviews were

not official events for those organizations where attendance may be mandatory or perceived as such).

Health care providers and professionals were individually invited to participate, voluntarily and without consequence. We sought to recruit providers and professionals at both the point-of-care level and the policy level.

### *Risks*

We identified minimal to no risks to participants but took measures to mitigate any potential risks that may stem from their participation, including ensuring anonymity in their participation, taking all reasonable measures to ensure privacy and confidentiality, and providing substantive consenting procedures. We informed participants of their rights—including their right to refuse to answer any question and to withdraw consent at any time, for any reason, and without consequence—prior to their participation.

### *Ethical review*

Georgetown University's Institutional Review Board (2018-1148) and Kenya Medical Research Institute's Scientific and Ethics Review Unit (Non-KEMRI No. 654 (2019)) approved this study following substantial and helpful review.

### *Data collection*

Data collection comprises (1) key informant and in-depth interviews (one to three persons per site, up to ten total) with health professionals (health care workers, policy experts, providers, and planners); (2) in-depth interviews with one to two self-identified members from each of the at-risk populations; and (3) focus groups with participants from at-risk populations (one focus group per population consisting of five to nine persons). Our study pre-tested the focus group and interview question guidelines before beginning data collection to ensure efficacy and sensitivity, utilizing individuals from key and affected populations and individuals with health professional backgrounds. All materials have been translated into Swahili and back-translated into English for fidelity. Data collectors utilize audio-re-

ording devices and note taking; transcriptions will be translated into English.

Data collection is ongoing at the time of this publication and is anticipated to conclude by July 2019, with analysis to follow.

We consulted with our community-based and civil society partners to identify and hire interviewers and moderators who are professionally capable and familiar with, if not members of, the respective at-risk communities.

### *Consent*

All participants are required to sign written consent forms prior to any discussion or data collection, and they must have the independent capacity to do so. All participants are offered multiple opportunities to ask for and receive information or answers to any questions, including prior to their consenting to participate. We ensure that participants know their rights regarding their participation, including the right to refuse and the right to withdraw consent.

### *Analysis*

#### *Qualitative analysis*

With the aid of appropriate software, we will analyze data under an exploratory grounded theory for qualitative research. With respect to HIV policies and practices, we will look for patterns and linkages in participants' experiences; code and evaluate commonalities and distinctions; and use that data to induce efficacy, opportunities, and challenges in Kenya's HIV testing and notification strategies. Identifying emergent themes in the data will inform our study's most salient outputs and, in particular, the breadth and depth of experiences and perspectives within key and affected populations' interactions with Kenyan health care workers and officials. Not every code or theme may have a direct human rights dimension, but in determining them, our work may identify actionable points for public health interventions.

#### *Rights analysis*

We are interested in whether the policies and practices employed by Kenyan health care workers and

professionals, and experienced by key and affected populations, are rights compliant. Predominantly, our study is focused on the human rights to free and fully informed consent, privacy, and confidentiality, which are codified under Kenyan law. Our rights analysis will broadly take a form reminiscent of the IRAC legal analytical tool:

- **Issue:** the code or theme under review emerging from the qualitative analysis.
- **Rule:** the pertinent human right(s) rule within the relevant domestic legal framework and under international human rights law.
- **Application/Analysis:** apply the rule to the issue and assess the risks or breaches to human rights—or the adequate protection and fulfillment of human rights—within the code or theme.
- **Conclusion:** determine how the specific human rights related to the code or theme are enjoyed by key and affected populations and upheld by health care providers.

We aspire to include analysts from the relevant at-risk communities, as we believe that implementation science in global health research should ensure that the communities in which such research occurs contribute to and benefit from such work.

### *Discussion and dissemination*

Our "Discussion" and "Recommendations" sections will identify opportunities, possible interventions, and challenges for Kenya's human rights-based approach to HIV testing and notification. Evaluating health programs from the perspective of rights realization creates a new metric for measuring efficacy and outcomes in HIV public health programs, through (1) identifying successful and sustained practices and policies within HIV testing and notification strategies that promote, protect, respect, and fulfill human rights, and (2) identifying any gaps and opportunities wherein the rights-based concerns of at-risk communities are not appropriately addressed as matter of policy or practice. Our

analysis may address issues such as the adequacy and sufficiency of health care provider training on human rights; the reach of best practices that support a human rights-based approach; and the necessary reforms to policy or practice in order to achieve both greater rights realization and (relatedly) trust and confidence in the health care system when it comes to HIV-related care and services.

Our dissemination plan is as follows:

1. Disseminate the research analysis to pertinent government and public health institutions in Kenya.
2. Disseminate the research analysis to the community-based and civil society organizations in Kenya that participated in its creation.
  - a. In addition, organize workshops, seminars, and meetings with key stakeholders (community members and representatives).
3. Publish our research in peer-reviewed journals and present it in suitable forums at the local, regional, and global level.

## Limitations

Certain limitations affect our study's scope and reach, and we hope that future projects will expand upon our research.

- Geographic limitations: our study focuses on Kenya, and primarily four counties within Kenya. Perspectives and human rights-related experiences may vary in other locations and contexts; perceptions on HIV-related stigma certainly do.<sup>15</sup>
- Representation limitations: our participants may not be able to comprehensively reflect the perspectives of every member of their self-identified group, especially those who may live in other contexts. While we hope to have sufficient sampling from each of the populations, future studies may go further by having a larger sample size or targeting additional demographics for inclusion (for example, refugees and the trans community).

- Language limitations: our participants will be required to speak comfortably in either English or Swahili.
- Other limitations: due to resource constraints, we excluded persons who could not independently consent to participate. Future studies may consider including adolescents and minors, persons living with certain disabilities, and persons for whom consenting may require extra processes (such as prisoners).

## Acknowledgments

We acknowledge the support provided by the staff of the Kenya Legal and Ethical Issues Network, including Ted Wandera, Lucy Ghati, Linda Kroeger, Naomi Monda, Jessica Oluoch, Anthony Mukheina, Flossy Nyagah, and Tracy Nyenze. We also appreciate the guidance of Joe Zunt, University of Washington (NIH/Fogarty-Northern Pacific Global Health Fellows Program); Carey Farquhar, University of Washington (Afya Bora Consortium); Matthew Kavanagh, Georgetown University (O'Neill Institute for National and Global Health Law); Theresa Odeero, University of Nairobi (Afya Bora Consortium); and Charles Muga, Kenya Medical Research Institute. We also thank our interviewers and moderators for their contributions: Pascal Macharia Irungu, Dorothy Awuor Agalla, Festo Collins Owino, Fatma Ahmed Jeneby, and Hussein Abdalla Taib. Finally, we appreciate the support of our community-based organization partners and recognize their invaluable role in the formation, implementation, and utilization of this study: Gay and Lesbian Coalition of Kenya, Health Options for Young Men on HIV/AIDS/STI, Kisumu Sex Workers Alliance, Family Health Options Kenya, and Muslim Education and Welfare Association.

## Funding

This project was supported by the National Institutes of Health (NIH) Research Training Grant D43 TW009345 funded by the Fogarty International Center, the NIH Office of the Director Office of AIDS Research, the NIH Office of the Director Of-

fice of Research on Women's Health, the National Heart, Lung and Blood Institute, the National Institute of Mental Health, and the National Institute of General Medical Sciences. This project was also made possible by the Afya Bora Consortium Fellowship, which is supported by PEPFAR through funding to the University of Washington under Cooperative Agreement U91 HAO6801 from the Health Resources and Services Administration's Global HIV/AIDS Bureau.

## References

1. AVERT, *HIV and AIDS in Kenya* (2018). Available at <https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/kenya>.
2. National AIDS and STI Control Programme, *2015 national HTS guidelines* (Nairobi: Ministry of Health, 2015).
3. AVERT (see note 1).
4. G. Githuka, W. Hladik, S. Mwalili, et al., "Populations at increased risk for HIV infection in Kenya: Results from a national population-based household survey, 2012," *Journal of Acquired Immune Deficiency Syndrome* 55/Suppl 1 (2014), pp. S46–S56; National AIDS Control Council, *Kenya AIDS response progress report 2016* (Nairobi: Ministry of Health, 2016), p. 51.
5. UNAIDS, *Greater involvement of people living with HIV and AIDS* (Geneva: UNAIDS, 2007).
6. See, for example, S. Dalal, C. Johnson, V. Fonner et al., "Improving HIV test uptake and case finding with assisted partner notification services," *AIDS* 31/13 (2017), pp. 1867–1876.
7. *Preventing intimate partner violence in Uganda, Kenya, and Tanzania: Summary of a joint workshop by the Institute of Medicine, the National Research Council, and the Uganda National Academy of Sciences* (July 24, 2015). Available at <https://www.ncbi.nlm.nih.gov/books/NBK316382>.
8. S. Kalichman, C. Mathews, M. Kalichman, et al., "Perceived barriers to partner notification among sexually transmitted infection clinic patients, Cape Town, South Africa," *Journal of Public Health* 39/2 (2017), pp. 407–414.
9. E. Moyer, E. K. Igonya, R. Both, et al., "The duty to disclose in Kenyan health facilities: A qualitative investigation of HIV disclosure in everyday practice," *SAHARA-J: Journal of Social Aspects of HIV/AIDS* 10/Suppl 1 (2013), pp. S61, S64, S66–70.
10. U.S. President's Emergency Plan for AIDS Relief, *Kenya country operational plan 2018: Strategic direction summary* (Washington, DC: U.S. President's Emergency Plan for AIDS Relief, 2018), pp. 41–42.
11. UNAIDS, *Human rights* (2019). Available at <http://www.unaids.org/en/topic/rights>.
12. Constitution of Kenya (2010), art. 31; *HIV and AIDS Prevention and Control Act* (2006), art. 3(b), 6(3), 14, 17, 18, 20, 21, 22; East African Community HIV and AIDS Preventions and Management Act (2012), §§19–32; World Health Organization, *Consolidated guidelines on HIV testing services 2015* (Geneva: World Health Organization, 2015), pp. 9, 39, 147; World Health Organization, *Supplement guidelines on HIV self-testing and partner notification 2016* (Geneva: World Health Organization, 2016), p. 58.
13. Kenyan National AIDS and STI Control Programme, *Key population* (2019). Available at [https://www.nascop.or.ke/?page\\_id=828](https://www.nascop.or.ke/?page_id=828); National AIDS Control Council, *2014/15–2018/19 Kenya HIV and AIDS research agenda* (Nairobi: Ministry of Health, 2015). Available at [https://nacc.or.ke/wp-content/uploads/2015/10/HIV\\_2.pdf](https://nacc.or.ke/wp-content/uploads/2015/10/HIV_2.pdf).
14. National AIDS Control Council (2016, see note 4), pp. 26–27.
15. *Ibid.*, p. 24.



**APPENDIX A****Focus Group Discussion Guidelines****INTRODUCTION BY MODERATOR (10 minutes)**

Hello, my name is <Name> and I am part of a research team working with the Kenya Legal and Ethical Issues Network on HIV and human rights. We are working with the University of Washington and Georgetown University to explore people's thoughts and opinions about HIV testing and notification, or disclosure, and respect for legal rights. We are interested in your participation in this focus group so that we can hear about your experiences and perspectives regarding health care and HIV. This will help us understand what is working and what is not in terms of supporting your human rights and HIV treatment.

This discussion is free and open; we want to hear your feelings and concerns so we can suggest improvements. Your participation is helpful, but you do not need to talk to us if you do not want to. You may stop participating at any time and without any consequence. We are recording this conversation, but your personal information—name, address, or other identifying information—will not be published. This conversation is private and confidential, and we ask all participants to respect one another. This is a “safe space” for us to discuss HIV and human rights in your community.

You are not required to provide, and we will not use, any personal information, including HIV status. We will use codes to refer to any participants, and the study will use neutral terms in English (“they,” “them,” and “their”) when referring to persons.

Do you have any questions?

Do you agree to begin this conversation?

*Obtain oral affirmation of focus group participants.*

*All participants will additionally consent in writing at the same time.*

**FOCUS GROUP DISCUSSION (60–90 minutes)****Engagement/warm-up**

1. Let's briefly introduce ourselves. This is for today's discussion only; your names will not be used in the study. Please say your name, your age, and something you like to do for fun.
  - a. *Moderator starts*
2. Survey question: Please raise your hand if you, your child, or a young relative has been to a health clinic or hospital in the past 12 months, for any reason.
  - a. Follow-up: How was your experience?
  - b. Follow-up: How were you received?
  - c. *To people who did not raise hands:* Do you have any reasons for not going to a health clinic or hospital?
    - i. *Follow-up probing based on responses*
      1. Example: Can you give an example from your own life or someone else's...?
      2. Example: This seems really important. Do you have anything more to say?
      3. *To others:* Do others have, or know people who have, experiences like this that they can share?
3. Generally speaking, do you feel you can trust health care workers with your information when you go to a clinic? (closed question)
  - a. *Follow-up probing:* Why or why not? Do you know any experiences that make it easier to have confidence in health care workers? Make it harder?

4. Have you ever felt pressured to do something related to your health or the health of a family member or friend?
  - a. *Moderator seeks a few examples.*
    - i. *Follow-up:* Have you ever done anything that you did not feel entirely sure about, but someone else really wanted you to?
5. Are you familiar with your legal and human rights such as:
  - a. A right to privacy concerning your information (meaning that nobody else can join or hear what you say with a health care worker if you do not want them to)?
  - b. A right to confidentiality (meaning that your information may not be shared with anyone you do not want to share it with, including health information such as HIV status)?
  - c. A right to fully informed consent (meaning that you may request, and must receive, any information you want about a procedure, including risks and benefits, before agreeing in writing to participate)?
  - d. A right to safety (meaning that you have a right to be free from abuse, discrimination, stigma, and violence)?
  - e. A right to dignity and autonomy (meaning that you must be respected at all times as a person who can make independent decisions for yourself or can choose who makes those decisions for you)?
    - i. *Follow-up:* Has anyone experienced, or feels their community has experienced, any issues or problems about these rights when dealing with health care workers and counselors?
      1. *Probe*
6. *For people who use drugs, sex workers, and men who have sex with men:* Generally speaking, how do you feel about:
  - a. Police
  - b. Health care workers
  - c. *Probing questions based on responses*

Exploration/main questions

1. As we know, HIV is a major health concern in Kenya. Many people like you in this group are thought to be at risk for HIV. Health care providers and Kenya's public health agencies recommend that more people test for HIV, especially people in your community. How do you feel about HIV today, in your community?
  - a. *Follow-up probing based on responses*
    - i. Example: Many people in your group are not testing for HIV. Why do you feel that is?
    - ii. Example: Do you think it is important to test for HIV?
      1. Who should test?
      2. Should we encourage testing? (*closed question*)
      3. Should we require testing? (*closed question*)
        - a. Why or why not?
          - i. *Note the human right to refuse to consent to testing*
    - iii. Do you feel that people in your community would feel safer testing:
      1. At home (self-testing)?
        - a. Why or why not?
          - i. *Probe for stigma/discrimination concerns*
      2. In a clinic?
        - a. Why or why not? (*group discussion*)
          - i. *Probe for stigma/discrimination concerns*
        - b. Are there any advantages to testing in a clinic?
          - i. Disadvantages?

2. One important part of a health care system is to protect your safety and privacy and to respect you as an independent person (*for people who inject drugs/men who have sex with men/sex workers: "regardless of your activities"*). This is especially true for HIV testing: testing should be private (between you and your health care provider) and confidential (your information should not be shared with anyone else without your consent). Your consent must always be voluntary and come after you feel you have all the information you need in order to decide whether to test.
  - a. Please describe how you feel about or any experiences with:
    - i. Nurses
    - ii. Doctors
    - iii. Administrators
    - iv. Insurers
    - v. Others (community)
    - vi. *For people who inject drugs/men who have sex with men/sex workers:* Police
    - vii. *Probing questions:* Did you feel respected when they spoke with you about your health?
  - b. Some of you might have tested for HIV, or friends or family may have tested for HIV. Under Kenyan law and international law, health care workers and hospitals must fully inform you about why testing is important and what it means to test, provide you with information, answer any questions you might have, and tell you about the benefits and risks of testing. Then, you decide whether you want to test without pressure or influence.
    - i. How do you feel about the way in which health care workers engage with people at risk for HIV, like those in your community?
      1. *Follow-up:* What could be better?
3. In addition to testing for HIV, notification or disclosure (sharing) of one's status with others can be an important way to find others who might be at risk for HIV and get them on treatment. This might be important for children of HIV-positive parents, husbands and wives, HIV-positive children whose parents do not know of their status, or any partners. At the same time, disclosure can put someone at risk of stigma, discrimination, and even abuse.
  - a. Do you feel there are any risks with disclosing or sharing HIV status?
    - i. *Probing:* Like what?
  - b. How do you feel about disclosing HIV status to others?
    - i. *Follow-up:* Who should disclose status?
      1. *Probing:* Should someone refuse to disclose their status?
        - a. *Ask for responses from other speakers*
    - ii. *Follow-up:* How should someone's status be disclosed?
      1. To whom? (parents, children, partners)
      2. When?
    - iii. Would disclosing HIV status be easier if a health care counselor or worker assists (e.g., assisted partner notification services)?
      1. Why or why not?
    - iv. When should someone's HIV status be disclosed without their consent?
      1. How should they be protected from any risks?
  - c. What can health care workers do to make you, and people like you, feel safer before and after HIV testing and disclosure?

#### Exit questions/wrap-up

1. Health care workers, before testing, must provide people with adequate pre-counseling. After testing, and before any disclosure or notification, they must also provide post-counseling. These are human rights in Kenya, and no testing should occur without fully informed consent.
  - a. What should be covered in pre-counseling before HIV testing (or, what would you



- a. Follow-up:* What are your primary responsibilities?
3. How would you describe a typical day at your work?

Interviewee: Public Health Policy Maker or Similar Professional

1. One of the reasons we wanted to chat with you is because of your experience working in HIV. Kenya and international authorities like PEPFAR want to meet the 90-90-90 goals, and that means increasing HIV testing. According to surveys, though, several key populations at risk for HIV are not testing enough.
  - a. Could you describe some of your experiences working with people at risk for HIV?
    - i. How have you engaged with people at risk for HIV?
      1. *Probing:* Which communities are you most familiar with? Least?
        - a. Probe for teenage mothers and pregnant teens, young and adult men, men who have sex with men, people who use intravenous drugs, sex workers.*
      2. *Follow-up:* What do you think, or know, are the major concerns or barriers for <key population>? *Note: this question relates to the 1–2 key populations identified in the preceding question.*
        - i. Probing:* Have you seen any efforts to address those specific concerns?
        - ii. Follow-up:* Has that worked?
  - b. Do you feel the <key population> understands the importance of HIV testing? *Note: this question relates to the 1–2 key populations identified in preceding questions.*
    - i. If yes:* What strategies do you think work, or what could work better that is not being done now?
    - ii. If no:* What strategies for outreach and inclusion might benefit these groups?
      1. *Listen and probe for health care provider engagement with or concerns about police (regarding people who inject drugs, men who have sex with men, sex workers).*
  - c. Do you feel all key populations are being addressed equitably?
    - i. Follow-up:* At this stage, our study is focused primarily on young women and men, two of the cohorts that undertest for HIV. Why do you feel they, specifically, are not testing?
    - ii. Probing:* What outreach is ongoing to other groups at risk for HIV, such as sex workers or men who have sex with men?
      1. *Probing:* Since these groups are often stigmatized, how well do you feel health care workers are mitigating that stigma?
    - iii. Follow-up:* What sort of training do health care workers receive when it comes to these groups (sensitivity, etc.)?
      1. Have training programs changed in the past 24 months?
        - a. Probing:* In light of the push for more testing, what sort of training do you think health care workers need or will need to increase rates in the key populations?
      2. With respect to health officials' goals, what sort of challenges do you feel must be overcome to increase HIV testing?
        - a. Listen for, or ask about human resources, effective outreach, stigma and discrimination.*
        - i. Probe based on responses.*
      3. Are health care workers receiving training on the legal and human rights of persons living with or at risk for HIV, including the following rights?
        - a. Right to provide fully-informed consent*
        - b. Right to privacy*



- c. Right to confidentiality
- d. Right to refuse
- e. Right to dignity and autonomy
- f. Right to safety (freedom from stigma, discrimination, abuse, violence)

Interviewee: Care Providers and Counselors

1. Health authorities (such as the Ministry of Health, NASCOP, and National AIDS Control Council) and foreign donors (such as PEPFAR) want to increase HIV testing and notification services in Kenya, through both increased resources and increased training.
  - a. Have you or colleagues undertaken training, such as sensitivity training, in the past 24 months related to HIV testing?
    - i. *If yes:* How would you assess that training? Did it help improve your practice? Did it help improve outreach to these communities?
      1. *Follow-up:* Following this training, do you feel you better understand and respect the concerns in these key populations?
    - ii. What could be improved?
      1. What would you like to know to better engage with these persons?
  - b. Have you or your colleagues undertaken rights-based training? In other words, have you or other health care workers been trained in patients' legal rights?
    - i. Did your training help you talk with patients about their legal rights, whether before or after HIV testing?
    - ii. Are health care workers trained to respect a patient's decisions, even if they disagree?
      1. *If yes:* How are they being trained?
      2. *If yes:* How would you assess that training?
      3. *If yes:* How could that training be improved to respect the patient and their concerns and to encourage more HIV testing?
2. Informed consent
  - a. What does informed consent mean to you or your organization?
  - b. Are there measures in place to ensure persons testing for HIV fully understand what the test is about before testing?
    - i. *Follow-up:* What measures are in place to ensure nobody is coerced or pressured into testing for HIV?
3. Privacy and confidentiality
  - a. What measures are in place to ensure a patient's information is private?
  - b. What measures are in place to ensure confidentiality with that information?
    - i. *Follow-up:* Does this include keeping information from other authorities, such as if a patient is a drug user or a sex worker?
      1. *If yes:* How is this ensured?
      2. *If yes:* How is this communicated to the patient?
  - c. Have you received particular training in privacy and confidentiality for HIV data?
4. Are health care workers communicating with people about privacy and confidentiality in pre- and post-counseling?
  - a. Thinking back to earlier questions, how do you feel trust for health services in these under-performing communities could improve?
5. Disclosure
  - a. Health authorities and donors want to identify more cases for HIV testing, particularly at-risk cases. As you know, index testing is an effective way to identify cases and get people on treatment.
    - i. Disclosing HIV status to third parties can be very risky to the index case. How do you and your colleagues initiate that discussion?

1. *Follow-up*: What are the concerns you hear from patients about disclosing their status?
  - a. *Probing*: How are those concerns addressed?
  - b. *Probing*: How can those concerns be better addressed?
- ii. What measures do you follow or know of to ensure a patient is fully informed about the benefits and risks for disclosure before they consent to it?
- iii. Are you and other health care workers trained to discuss disclosure?
  1. How would you assess the training?
    - a. *Probing*: Is it effective? Are there things you would like to know more?
    - b. *Follow-up*: What might improve training or improve health care workers' abilities to connect with patients and discuss disclosure?
  2. Do health care workers receive training to spot potential risks to the index case from disclosure?
    - a. *Probing*: A major concern in Kenya is violence and abuse, especially against women. This is especially true for HIV-positive women and children who might face stigma, discrimination, or abuse from family, partners, and their communities. How have you been trained to identify risks for harm when disclosing an index case's HIV status?
      - i. What methods do you and your organization follow when disclosing? (assisted partner notification services, for instance)
        1. *Probing*: How would you assess your training in those methods?
- b. As before, the legal rights of patients are important parts of disclosure. Consent is typically required, and respect for their issues and even refusal to consent.
  - i. Are health care workers trained in the legal rights around disclosing status to third parties?
  - ii. Do health care workers inform patients of their legal rights prior to disclosing status to third parties?

### Conclusion

We appreciate you taking this time to share your views and opinions. As a reminder, we have recorded this conversation and will maintain your privacy and confidentiality. Your name and any identifying details will not be published.

Are there any details you would like to share with us that we have not asked?

Are there any final suggestions or comments you would like to make?



## BOOK REVIEW

## Assessing Human Rights in Global Health Governance

JULIE HANNAH

***Human Rights in Global Health: Rights-Based Governance for a Globalizing World*, edited by Benjamin Mason Meier and Lawrence Gostin, published by Oxford University Press, 2018**

Institutions matter, and institutions of global health governance are increasingly implementing human rights to advance global health. This is the central contention of *Human Rights in Global Health: Rights-Based Governance for a Globalising World*, a unique and comprehensive survey of global institutions, public health, and the institutional mainstreaming of human rights.

The book, published in May 2018, is already a celebrated piece of scholarship. It has been praised in many reviews, and its contribution to the health and human rights field will likely continue for years to come. Indeed, the collection represents an enormous and successfully executed undertaking that makes a significant contribution to the health and human rights field. It presents a snapshot of a moment in history when global health institutions and human rights are under massive pressure. History plays a central role in the volume, contextualizing past struggles, achievements, and lessons learned.

The book's main purpose is to provide an introduction to and assess the relationship of human rights within global health governance. Governance for global health is defined in the book as the provision of "expert policy guidance, financial and technical assistance, normative standards, and accountability mechanisms" (p. 3). Importantly, the book conceives of health broadly and features a range of global institutions—including the World Health Organization, the International Labour Organization, and the World Bank—that engage not only in health care but also in the underlying determinants of health. This diverse reflection produces an intriguing narrative of the complex institutional experience of global health and human rights.

While an expansive volume—just under 600 pages—the book remains surprisingly accessible. Much of this is owed to the consistent and deliberate structure of each section, which is much to the credit of the book's editors, Benjamin Mason Meier and Lawrence Gostin, both indefatigable global health scholars and practitioners. The five sections of the collection cover 24 chapters, with more than 40 contributing authors.

The first section focuses on the historical and conceptual frameworks for global health and human rights. Chapter two, by Alicia Ely Yamin and Andrés Constantin, richly recounts two decades of the health and human rights movement and should be required reading (indeed, the entire volume should be) for any introductory public health or human rights course. The final chapter, like each concluding chapter of subsequent sections, looks to the future and critically reflects on what lies ahead for global governance in health and human rights.

The second section focuses on the historical, current, and future of human rights engagement at the World Health Organization. The final chapter is a plaintive call for leadership to sustain the rights-based progress made and to advance institutional mainstreaming more broadly.

A selection of inter-governmental organizations is presented in section three, including an insightful review and candid critique of human rights engagement at the International Labour Organization by Lee Swepston. While the volume cannot include reflections on every inter-governmental organization, it would have been interesting to see chapters on human rights engagement from organizations responding to other

topical global health and rights crises, including the United Nations High Commissioner for Refugees and the International Organization for Migration on migration and human rights, and the United Nations Office on Drugs and Crime on the opioid or global pain crises and human rights. This is certainly something for the editors to consider in a second volume.

The fourth section draws out the contested human rights terrain of global economic governance and multilateral funding and is perhaps one of the more critical sections of the volume. With an introductory chapter framing rights-based approaches to development within global governance for health by Stephen Marks, the section explores the World Bank, the World Trade Organization, the Global Fund, and the future of multilateral funding.

The institutional gaze shifts to the United Nations human rights machinery in the fifth and final section. The opening chapter of this section focuses on the Office of the High Commissioner for Human Rights and the evolution of the right to health from within the office. Gillian MacNaughton and Mariah McGill paint a grim picture of an under-resourced institution where health-related work is not a programmatic priority, with only one full-time staff member working on the right to health. The final three chapters of the section capture more encouraging perspectives of the rich normative development on health from the special procedures and treaty body systems and the emerging political engagement and promise of the Universal Periodic Review at the Human Rights Council.

The list of authors is formidable and includes leading scholars and senior members of the vast United Nations machinery. Nineteen of the authors are either current or former members of staff in the global governance mechanisms discussed. Many have cut their teeth on the frontlines of health and human rights activism, which allows, at times, for a robust and critical reflection on the challenges, opportunities, and future for human rights in global institutions. A reader would be hard pressed to find any other collection of global rights leaders who offer such insights into these institutions' culture

and politics.

However, the fact that many of the authors—while highly respected thinkers and colleagues—are decidedly “inside” voices does require the reader to accept that some chapters may present a less critical view. While the degree to which critical reflection is featured in the chapters is variable, the skeptical reader may be pleasantly surprised by the candor with which some of the authors reflect on institutional challenges, at times offering incisive and fascinating personal perspectives.

For students and scholars alike with an interest in the current foundations of global health and human rights, this book is an accessible and comprehensive introduction to global governance for health. However, readers with a strong interest in understanding the instrumental and catalytic role of civil society in the successes highlighted will not be entirely satisfied. Again, something to consider for a future collection.

And while institutions matter, the book highlights that the leadership and courage of *people* who staff these institutions are powerful components of rights-based change. From the early leadership of Jonathan Mann at the World Health Organization, to the campaigning of Mary Robinson at the Office of the High Commissioner for Human Rights, to the global health and human rights leaders of tomorrow—people matter.

It is also *people* who are directly affected by global institutions, for better or for worse.

As the authors from UNAIDS (chapter four) state:

*The practice of global health governance today is overly technocratic, specialized, and inaccessible to the people it is meant to serve ... Now is the time for the global health community to take stock, to critically revisit its values, and to consider how development approaches must be reformed to achieve the SDGs and promote the realization of human rights for global health. (p. 90)*

The synergistic relationship between people and governance institutions as understood by affected communities is perhaps a missing voice from this collection. One volume cannot be all things, but



this absence will hopefully inspire a second volume to invite contributions from affected communities themselves who respond to critical questions: How have global governance mechanisms supported meaningful change in their everyday lives? What struggles and cautionary tales can these institutions learn for future sustainability? These voices must remain central not only to institutional programming and practice but also to the scholarly discourse around global health governance and human rights.

*Julie Hannah is director of the International Centre on Human Rights and Drug Policy at the University of Essex, UK, and an advisor to the United Nations Special Rapporteur on the right to the enjoyment of the highest attainable standard of physical and mental health.*



## BOOK REVIEW

## Being Bold about Rights in a Neoliberal World

AUDREY CHAPMAN

*Economic and Social Rights in a Neoliberal World*, edited by Gillian MacNaughton and Diane F. Frey, Cambridge University Press, 2018

Neoliberalism, the dominant political ideology and economic and political policy during the past 40 years, poses significant challenges for human rights, particularly economic, social, and cultural rights. Also referred to as market fundamentalism, neoliberalism maintains that human well-being can best be advanced within an institutional framework characterized by free markets, a minimal state, free trade, the absence of economic regulation, and strong individual property rights. Neoliberal doctrine seeks to reduce the role of the state on which human rights depend for protection and implementation, including to diminish or even eliminate its social and welfare responsibilities. A goal of neoliberalism is to cut public expenditures for social services such as health and education, including reducing welfare programs and the safety net for the poor, with policy makers often arguing that generous entitlements are unaffordable while enacting tax cuts benefiting the wealthy. Neoliberalism also advocates for privatizing infrastructure, utilities, and social services through selling them to private investors or transferring their management to the private sector. Moreover, the neoliberal outlook does not acknowledge social and economic rights as being legitimate human rights or even genuine entitlements because in their market-based framework no one has a claim on the resources from society necessary to provide adequate food, education, housing, and health care.<sup>1</sup>

Nevertheless, despite the challenge that neoliberalism poses, there is not much human rights literature examining the impact of neoliberalism on specific social and economic rights and in different national contexts. Gillian MacNaughton and Diane Frey's recently published edited volume *Economic and Social Rights in a Neoliberal World* is therefore a welcome addition to the literature. The volume is the product of the International Research Collaborative on Economic and Social Rights in a Neoliberal World, an initiative supported by the Law and Society Association. This volume is truly an international effort. The authors who contributed chapters to the volume come from eight countries, and their chapters examine economic and social rights in the context of neoliberalism in eleven countries: Brazil, Colombia, Ecuador, Egypt, Israel, Mexico, New Zealand, Peru, South Africa, South Korea, and the United States. In addition, there are chapters addressing the role and policies of the International Labour Organization (ILO) and the United Nations Committee on Economic, Social and Cultural Rights, the oversight body for the International Covenant on Economic, Social and Cultural Rights. None of the chapters, however, focuses on the right to health. The volume also has an introduction setting out the issues and providing an overview of the content of the chapters along with a conclusion drawing together the findings from the various chapters.

The volume seeks to address three major issues. The first is to identify the specific ways in which the requirements of economic and social rights conflict with neoliberalism. The second is to assess whether economic and social rights are effective, or at least have the potential to be effective, in countering neoliberal ideology and policy. The third is to evaluate the extent to which neoliberalism affects the interpretation and implementation of economic and social rights. The introductory chapter sets forth these issues, and then the final chapter draws on the contributions to the volume to seek to provide answers. The conclusion

also considers a fourth question: How can we engage economic and social rights most effectively to challenge neoliberalism?

The volume contains 15 chapters divided into four thematic sections. The editors' introduction provides a good overview of neoliberalism, its impact on human welfare, and the issues it raises for economic and social rights, as well as setting forth the organization of the volume and describing the content of the chapters. Chapters in the first section establish a foundation for understanding the interaction of neoliberalism with economic and social rights using a variety of multidisciplinary lenses. Several of the chapters in this section are particularly notable.

The two chapters in this section exploring the relationship between neoliberalism, human rights, and economic inequality address an important and too often neglected topic in the discourse on economic and social rights. Under neoliberalism, economic inequalities have grown markedly both within and between countries as a consequence of the dynamics of capital accumulation under advanced capitalism and the neoliberal economic and political policies adopted that favor corporations and the affluent. Inequality has spiked in both developing and developed countries. So an important question is whether human rights can make a difference. James Heintz's chapter contrasts how neoliberal economics and the human rights framework engage with questions of inequality and the extent to which human rights practice challenges neoliberal and neoclassical approaches to inequality. He concludes that the human rights framework provides some guidance on the implications of widening inequalities and its implications for the fullest realization of human rights but that it does not identify a particular distribution of wealth as just.

Gillian MacNaughton's chapter goes further in addressing the potential of human rights to promote equality. In contrast with human rights analysts that do not believe that there is a human right to equality, MacNaughton proposes that it is time to recognize the possibility that the right to equality in the Universal Declaration of Human Rights and international human rights treaties

extends to economic and social rights as well as to civil and political rights. She urges scholars and practitioners to move beyond neoliberal constraints to consider ways in which rights to equality and nondiscrimination could be reinterpreted to achieve this goal. Doing so would then enable the international rights to equality and nondiscrimination to address economic and social inequalities and in the process make "equal in dignity and rights" meaningful to all. Another advantage is that it would also enable human rights to more effectively challenge neoliberal policies.

Several other chapters in the first section deal with empirical issues or specific rights in particular countries. Felipe Ford Cole details the path that neoliberalism's proponents took to embed neoliberal ideology into law in Peru. Asa Maron's chapter documents how neoliberal governance prescriptions and the growing primacy of economic modeling have subordinated social goals to administrative goals geared toward the efficient management of scarce resources focusing on the situation of at-risk children in Israel. A chapter written by James Murphy argues that neoliberal thinking has been detrimental to the socializing function of education by fostering an ethic of hyperindividuality, cynicism toward collective action, and acquiescence to the social order.

Section two of the volume addresses conflicts of neoliberalism with economic and social rights in times of crisis. The diverse crises examined include the financial crisis of 2008, the situation in Egypt following the 2011 uprising, efforts to deal with violence against women in Mexico, and post-conflict peacebuilding mechanisms. Some of the chapters in this section do not comfortably fit the focus of the volume other than documenting the lack of attention to social and economic rights. In some of these contexts, the failure to address economic and social rights could be for a variety of reasons other than neoliberal ideology.

Ben T. C. Warwick's chapter in this section assesses the response of the Committee on Economic, Social and Cultural Rights (CESCR) before, during, and after the 2008 financial crisis. Reviewing the committee's output, Warwick maps the CESCR's

greater level of comfort in dealing with obligations related to nondiscrimination, immediate obligations, and progressive realization and its reluctance to cite violations related to retrogression and the nonimplementation of the minimum core of rights. Without a clear explanation, he claims that this order of preference has a degree of correlation with the values of neoliberalism rather than challenging neoliberal priorities. He also raises the question of whether the CESCR's conciliatory approach and its praise for the progress made by states might reflect a subtle ingestion of neoliberal ideology. However, as a veteran CESCR watcher, I think he discounts the CESCR's consistently overly diplomatic approach to reviewing country reports and its reluctance to use violations language. CESCR has generally been more progressive and forthcoming in its general comments and statements than in its analyses of state parties' reports. For example, a 2012 letter of the chairperson of the committee to state parties of the International Covenant on Economic, Social and Cultural Rights about austerity programs emphasizes that any proposed policy change or adjustment must meet a number of requirements. The requirements include that the policy must be a temporary measure; the policy must ensure that the rights of disadvantaged and marginalized individuals and groups are not disproportionately affected; and the policy must ensure the protection of the minimum core content of rights.<sup>2</sup> The committee also issued a statement on the requirements of maintaining social protection floors in 2015 and a statement on public debt, austerity measures, and the International Covenant on Economic, Social and Cultural Rights in 2016.<sup>3</sup> The 2016 statement imposes obligations on both borrowing and lending states to carry out a human rights impact assessment in order to ensure that the conditionalities do not lead to violations of the rights in the covenant.<sup>4</sup>

Chapters in part three grapple with the tension between economic and social rights and the tenets of neoliberalism in the context of development and the provision of development aid. The goals of development—namely growing the economy and widely distributing the benefits of this growth—are constrained by the global neoliberal policy envi-

ronment, particularly its stipulations against direct government intervention in favor of market-oriented solutions.

Sakiko Fukuda-Parr has an insightful chapter that contrasts how Brazil and South Africa have implemented a commitment to a right to food while pursuing free market economic policies. The chapter compares Brazil's national policy for food and nutritional security, which is comprehensive in scope and seeks to address the long-term structural causes of food insecurity, with South Africa's strategy that focuses on relief measures that provide a short-term safety net. She attributes this difference to Brazil's willingness to proactively intervene in the market while South Africa, more wedded to traditional neoliberalism, has been reluctant to do so.

Carmel Williams and Alison Blaiklock scrutinize the impact of neoliberalism on New Zealand's development aid to test the hypothesis that the socioeconomic rights informing the Sustainable Development Goals (SDGs) are in practice being undermined by neoliberal values, contracts, and trade arrangements. Their chapter shows that while the New Zealand Aid Programme identifies sustainable economic development as the overarching framework for its activities, in reality its own priorities, particularly the importance given to private-sector-led growth, shape aid activities. Williams and Blaiklock attribute the ease of this cooptation to the weak and voluntary accountability framework for the SDGs and the failure of the framers to embed legal human rights. To compensate for these omissions, they recommend that United Nations human rights treaty monitoring bodies incorporate SDG monitoring into their reviews of states' implementation of their human rights obligations.

In the last chapter in this section, Joo-Young Lee studies how South Korea's combination of neoliberalism and a developmental state has constrained implementation of the economic and social rights enshrined in the South Korean Constitution. She attributes the failure of economic and social rights to play a role in countering or ameliorating the worsening social inequalities in recent decades to the historic dedication of the South Korean state



to a growth-first ideology and the reluctance of the Korean Constitutional Court to give normative force to economic and social rights. In contrast with human rights values, both Korean developmentalism and neoliberalism place a priority on capital accumulation and perceive labor and social security as costs that undermine growth and competitiveness. According to her analysis, economic and social rights also suffer from very weak mechanisms of accountability. However, she notes that the increasing disillusionment of a large segment of South Korean society with the growth-first and trickle-down effects may change the calculus in the future.

The chapters in the final section ostensibly focus on how neoliberal pressures affect accountability mechanisms for economic and social rights. However, not all of the chapters in this section do so. Jean Carmalt's chapter uses geographical analysis to show how the implementation of neoliberal policy is characterized by spatial practices with results that violate international human rights standards. LaDawn Haglund's chapter explores water and sanitation rulings of courts in São Paulo, Brazil, to identify conflicts between economic and social rights and neoliberal economic rationality. Neoliberal economic principles, such as full-cost recovery and market-based allocation, block the provision of essential water to people who cannot afford to pay for it. She finds that working with the judiciary and explicitly articulating human rights standards can be beneficial for progressive social change in cases dealing with water and sanitation access.

Diane Frey's chapter in the fourth section explores the contradictions and active conflicts between neoliberal and social justice advocates at the ILO through a presentation of three case studies. The ILO uniquely among international bodies has a tripartite structure representing workers, employers, and governments. As might be expected, she finds that the workers as a group have most faithfully protected the inherited justice values and purposes of the ILO's mandate. To date, their commitment has been sufficient to maintain the integrity of many social justice labor rights against efforts to neoliberalize them, but she cautions that this may not necessarily be the case in the future.

The concluding chapter draws on the book's 15 chapters to assess what they reveal about the questions posed in the introductory chapter. The first question concerned the ways in which economic and social rights conflict with neoliberalism. Virtually all of the chapters demonstrate facets of this conflict. To avoid repetition, the review will not reiterate the ways in which they do so.

The second question concerned the extent to which economic and social rights are effective in countering neoliberal ideology and policy. Frey and MacNaughton's assessment is that several of the chapters show that economic and social rights have made a difference on specific issues in specific places at specific times or currently are in play to do so. They cite case studies in Frey's chapter on the ILO; the instance described in Cole's chapter on Peru in which activists successfully stopped a neoliberal law reform that would have created a youth underclass of workers; and the way that litigants in Haglund's chapter on Brazil successfully utilized human rights in their claims for basic water and sanitation services. On the other hand, they acknowledge that other chapters—in fact most of the chapters in the volume—describe cases in which economic and social rights have not been effective in protecting vulnerable people in the face of pervasive neoliberal policies.

The third issue is the extent to which economic and social rights are interpreted or implemented in a way that is consistent with neoliberalism. This review has already taken issue with one of their key cases, Warwick's interpretation of the response of the CESCRC to economic crisis. MacNaughton's chapter on inequality questions the narrow interpretation of equality rights by treaty bodies and by human rights scholars. While this narrow view of equality rights in international human rights law coincidentally agrees closely with the neoliberal policy framework, she does not claim it has resulted from a conscious effort to align the two. Lee's chapter on South Korea also illustrates that the interpretation of economic and social rights related to a wide range of social policies in that country is consistent with neoliberalism. As a consequence, the CESCRC reported its concerns over these det-

rimental policies on the enjoyment of economic and social rights in its review of South Korea in 2001 and again in its review in 2009. However, as MacNaughton and Frey acknowledge, the CESCR's observations, like South Korean constitutional rights, are likely to remain ineffective.

So where does that leave those of us committed to economic and social rights? Several chapters in this volume provide a range of concrete ideas for an agenda to strengthen the role of economic and social rights and to improve accountability at the level of human rights treaty bodies. Recognizing a right to economic equality as MacNaughton proposes would likely make a considerable difference. Frey and MacNaughton also point out that some of the contributions, particularly Fukuda-Parr's chapter describing Brazil's implementation of the right to food, show that countries can make substantial progress in realizing economic and social rights when there is political will to do so. Supervisory mechanisms as described in Frey's chapter on the ILO can also play an important role in supporting economic and social rights in situations where they are threatened by neoliberal orthodoxy. Frey and MacNaughton's concluding advice is that "we must persist in making economic and social rights more visible to more people everywhere, and be bold and creative in asserting these rights in the era of neoliberalism."<sup>5</sup>

MacNaughton and D. F. Frey (eds), *Economic and social rights in a neoliberal world* (Cambridge: Cambridge University Press, 2018), p. 353.

## References

1. A. R. Chapman, *Global health, human rights and the challenge of neoliberal policies* (Cambridge: Cambridge University Press, 2016).
2. A. G. Pillay, Chairperson Committee on Economic, Social and Cultural Rights, letter dated 16 May 2012 addressed by the Chairperson of the Committee on Economic, Social and Cultural Rights to States parties to the International Covenant on Economic, Social and Cultural Rights.
3. Committee on Economic, Social and Cultural Rights, *Statement on social protection floors: An essential element of the right to social security and of the sustainable development goals*, UN Doc. E/C.12/2015/1 (2015).
4. Committee on Economic, Social and Cultural Rights, *Statement on public debt, austerity measures and the International Covenant on Economic, Social and Cultural Rights*, UN Doc. E/C.12/2016/1 (2016).
5. D. F. Frey and G. MacNaughton, "Conclusion," in G.

