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EDITORIAL

Global Social Medicine for an Equitable and Just Future

CARLOS PIÑONES-RIVERA, ÁNGEL MARTÍNEZ-HERNÁEZ, MICHELLE E. MORSE, KAVYA NAMBIAR, JOEL FERRALL, AND SETH M. HOLMES

The papers in this special section work together to move toward a global social medicine for the 22nd century. They envision a global social medicine that confronts and moves beyond the traditionally colonial, xenophobic, heteronormative, patriarchal, gender-binary-bound, capitalist, and racist histories of the fields of global health and human rights. They seek to instantiate a global social medicine that centers knowledge and experiences from the Global South and works toward social justice and health equity at scale. In this special section, the authors are particularly interested in understanding, challenging, and expanding our perspectives and enactments of the right to health. Unlike neoliberal perspectives on health that often limit their explanatory capacity to how individuals behave in the world, the papers here move beyond the focus on lifestyles and on the phantasmagoria of a sovereign subject with supposedly free agency. Instead, authors work toward critical consciousness that accounts for structural processes—with their inequities and disruptions, as well as their effects on individuals—and how this consciousness can open new horizons for collective transformation and social emancipation in health.

These papers build on a long history of theorizing and critiquing coloniality and racism. The seminal works of Frantz Fanon (in the Antilles and beyond), W. E. B. Du Bois (in the United States), and Aníbal Quijano (in Latin America), to name only a few in the Antilles and beyond, theorize systemic racism and its intersections with colonialism.[1] These and other thinkers lay the groundwork for critical applications to diverse fields. In particular, these contributions are the foundation of key critiques of racism, colonialism, and neocolonialism in science and biomedicine, elucidating how these structural processes impact individual and collective health.[2] Such forces condemn some human groups not only to exclusion but to pure and hard "extinction."[3] This critical work on colonialism and racism has also shaped the framework of critical interculturality in health, which recognizes the weight of the coloniality of knowledge from Global North and Eurocentric perspectives and stresses the need for epistemology from the Global South and from social movements around the world.[4] Critical interculturality imagines a science that is critical and emancipatory

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and that serves people and collectives instead of those in power, such as nation-states and corporations. It also envisions the potential of a "critical consciousness of oppression" as a starting ground for individuals and social groups to transform the world.[5] Latin American thinkers have been developing this framework in relation to Latin American social medicine and collective health.

These critiques at the intersection of racism, colonialism, and medicine remain relevant today in the wake of so many recent tragedies, such as the deaths of Joane Florvil, Jina Mahsa Amini, George Floyd, and many others at the hands of the police and other violent institutions. Simultaneously, the continued rise of violent anti-immigrant xenophobia alongside new expressions of white supremacy and anti-Black and anti-Indigenous racism all continue to impact collective health. In response, 21st-century reflections and actions against coloniality and racism are changing, deepening, and broadening.[6] Within academic discussions, authors argue for the importance of decolonizing global health and advocate for an intercultural turn in health.[7] Scholarship on capitalism's relationship to modern-day medical institutions outlines structural determinants of health; and the framework of collective health broadens this analysis by stating that the movement of capital accumulation subsumes particular modes of living and embodies the phenotypic, genotypic, and psychological processes expressed in epidemiological profiles. In addition, major medical journals related to medicine focus on the importance of racism on multiple levels.[8] These analyses clarify how various historical and contemporary social and economic structural forces continue to impact the right to health.

In approaching this special section, we acknowledge that certain groups in power, especially in the Global North, have dominated the literature on the right to health. In order to counteract the forces of what Latin American theorists have termed "scientific ignorance," we attempt to bring into dialogue multiple frameworks that can help us understand the breadth and depth of the right to health from distinct social, disciplinary, and geographic locations around the world.[9] The pa-

pers in this special section reflect insights from the fields of social medicine, collective health, Latin American critical medical anthropology, the Indigenous research paradigm, health and human rights pedagogy, and structural competency. These contributions reflect ways to think and act from Africa, South Asia, Latin America, North America, Western Europe, and Eastern Europe, and are in conversation with one another as we work toward a better—perhaps deeper and broader—understanding of the right to health, global health equity, and social justice.

Taking a rights-based and decolonial approach is critically important to expand the literature on the right to health from multiple social and geographic angles and to gather analyses from communities and territories with a long history of struggle against colonialism, racism, and other systems of inequity, accumulation, and dispossession.[10] In different ways, the papers included in this section seek to redefine their relationship with the communities and collectives with whom they work and form part. These analyses seek to strengthen the recognition of other logics—logics that are not only different from the sources that have nourished social medicine but also distinct from those that have nourished scientific knowledge; logics that are markedly diverse and non-Eurocentric. This allows for the validation of subalternized, popular, and Indigenous knowledge, illuminating dimensions of reality made invisible by scientific ignorance while pushing toward a more just social medicine.[11]

Building from Paul Farmer's legacy

This special section was developed to honor and build upon the legacy of Paul Farmer, who died suddenly one year ago (on February 21, 2022). Farmer's work had profound impacts worldwide on those who knew him and those who, even without knowing him personally, were inspired by his work.

In his writing and actions, Farmer sought to broaden the horizons of human rights. This is reflected clearly in his paper "Challenging Orthodoxies," in which he introduced his plans for *Health and Human Rights Journal* as incoming edi-

tor-in-chief.[12] In this paper, he invites us to broaden the right to health toward the economic and social rights that allow us to work toward global health equity. Beyond his many publications pushing toward global health equity, his legacy is seen in his active "pragmatic solidarity" as the co-founder of Partners In Health, including his activism and advocacy.

In this special section, we honor the legacy of Paul Farmer by following his iconoclastic stance, working to expand the horizon of the right to health, changing whose voices are centered, and broadcasting the experiences and knowledge too often ignored by hegemonic perspectives. In these ways, we work to build a social medicine for the 22nd century that works against racism and colonialism on all levels, from intrapersonal to interpersonal, epistemic to material, and institutional to structural. In honoring Farmer's legacy, we learn from and acknowledge the myriad scholars and traditions that shaped his work, from Fanon to Galtung, liberation theology to decolonial praxis, Latin American social medicine to critical medical anthropology thinkers such as Paola Sesia and global health equity leaders such as Agnes Binagwaho (both of whom have commentaries in this special section). The lineages of thought and action that compelled Farmer are historically deep and geographically broad.

Broadening the right to health

This special section aims to provide a space for interaction and dialogue among diverse voices working for global social and health justice. Its papers result from practices that struggle to broaden the predominant meaning of both human rights and health itself.

The paper by Mireia Campanera, Mercè Gasull, and Mabel Gracia-Arnaiz utilizes the framework of the social determinants of health to interrogate the structural aspects of food insecurity. Through an ethnographic study carried out in Catalonia, Spain, with primary health care teams, this paper focuses on the lack of responsiveness of these professionals to the basic needs of the most

oppressed social groups. Although health and social policies speak of the need to consider the social determinants of health—especially after the 2008 economic crisis—primary health care practices have achieved little concerning these determinants. The authors argue that scarce resources at the primary health care level and the lack of training for professionals to transcend the individualistic view of health and food insecurity result in the failure to respond to the social determinants of health. Considering food from a human rights perspective, this paper discusses the reduction of food to a matter of mere individual responsibility while concealing the political dimensions of a fundamental right on which health closely depends.

A number of papers carry out this broadening of the horizon of right to health using the tools provided by the relatively recent framework of structural competency. Each takes a clinical problem as a starting point and then shows the problem's structural determination. These papers broaden the right to health by underlining the critical importance of structural processes.

Margaret Mary Downey and Ariana Thompson-Lastad, for example, establish that "structural competency and the right to health are complementary frameworks that should inform each other." In the process, they make innovative and compelling connections between the social determinants of health approach and what C. Wright Mills conceptualized as the "sociological imagination."[13] Their work focuses on medical social workers in a maternal and child wellness center, as they conceptualize individual troubles as part of larger societal issues produced by imbricated institutional, structural, and historical forces beyond the control of any one person.

Along a similar line, Michele Friedner brings disability justice explicitly into the nexus of the right to health and the framework of structural competency. Her paper analyzes the Indian program to promote biotechnical assistance to deaf children (including cochlear implants) living below the poverty line. She argues that by focusing solely on the "right to hear" and cochlear implants as a response to deafness (as opposed to other forms of

social and medical inclusion), health professionals ignore the complex work required to maintain cochlear implant infrastructures, as well as the advocacy work done by disability activists in India. She advocates for including disability justice as a core aspect for structural competency and the right to health. Her proposal is consistent with and broadens the United Nations Convention on the Rights of Persons with Disabilities, which promotes the right of persons with impairments to live a full and dignified life.

A similar line of intersection between structural competency and the rights-based perspective is proposed by Michelle Munyikwa, Charles Hammond, Leanne Langmaid, and Leah Ratner. They address the difficulties in the transition from pediatric to adult care for adolescents and young adults living with medically complex chronic diseases. The authors' argument is that a safe, structurally aware, and interpersonally supported transition to adult services is a key component of the right to health for all people, especially for youth dealing with medical complexity and structural vulnerability. Including concrete cases from the United States and Ghana, the paper offers vivid images of the transition from pediatric to adult care, illuminating the importance of structural aspects such as stratification between public and private health insurance systems. The authors aim to produce a structurally responsive and equitable transition medicine that includes empathic attitudes and material means. The text broadens the horizon for perspectives on structural competency while offering a useful model for this health care transition.

Although the work of Marek Szilvasi and Maja Saitovic-Jovanovic is not explicitly situated in relation to the structural competency framework, their perspective is perfectly compatible with the aspect referred to as "structural humility."[14] Their paper analyzes Roma community-led initiatives using social accountability and legal empowerment approaches to advocate for equitable fulfillment of the right to health. The argument is grounded in the pioneering work of Anuradha Joshi, who complements social accountability and legal empowerment approaches, following the legacy and

broadening the important work on social accountability developed in South Africa, Latin America, Indonesia, and South Asia.[15]

Szilvasi and Saitovic-Jovanovic explicitly recognize that the quality, affordability, and inclusiveness of health care systems are determined by what they call, following the work of Jo Phelan and Bruce Link and of Scott Stonington et al., "fundamental determinants of health."[16] Szilvasi and Saitovic-Jovanovic's paper is instructive regarding the concrete difficulties that the development of structural competence can encounter not only in health teams but also in the very collectives and communities that fight for their rights, something that Carlos Piñones-Rivera and colleagues have called "collective structural competences."[17] The authors point out the need for further efforts toward collective, advocacy-focused, and community-driven actions that tackle structural factors determining the right to health. Following Farmer, they argue that we must go beyond a right to health care, integrating all of the aspects of social, economic, and political life that determine health.

When the points of view of Indigenous peoples are considered, the right to health is broadened in important ways. This special section includes two papers that reflect experiences of struggles for the right to health within Indigenous communities in South America in relation to understandings from collective health and critical interculturality in health. Both show the colonial condition within neoliberal capitalism, the impact it has on the individual and collective health of Indigenous peoples, and how communities theorize and organize to confront this oppression.

Adimelia Moscoso, Carlos Piñones-Rivera, Rodrigo Arancibia, and Bárbara Quenaya analyze their collaborative work as Indigenous (Aymara) people and allies in Chile to problematize the very matrix from which the right to health is defined and explore the advantages of situating work in an Indigenous research paradigm.[18] This epistemological shift arises from the need to decolonize research, which at times considers Indigenous peoples to be only objects of investigation and not producers of knowledge themselves, who may have their

own epistemological and even ontological logics.[19] Specifically, analyzing the death of an Aymara wise woman, and the sociolegal strategy used to confront the lack of cultural appropriateness in health care, this paper highlights how colonial logics are reproduced in the field of the right to health care, denying other ways of producing evidence to demonstrate the violation of health care rights. In doing so, the authors build from understandings of collective health to argue that research on the right to health must confront and counteract the hegemony of a limited biomedical gaze over the knowledge of Indigenous peoples.

Along the same line, Marcela Castro and Ana María Alarcón's paper provides insights into how the Mapuche people strive to fulfill their Indigenous rights to land and health within a profoundly unequal racial capitalist, colonial, global market system. Based on interviews with Mapuche people from diverse sociocultural roles, the authors explore the knowledge that Mapuche people from the Araucanía (Chile) have about nature, well-being, and their relationships with the Chilean state. Through the voices of Mapuche interviewees, Castro and Alarcón guide us into critiques of the extractive policy implemented by the Chilean state; the colonial logic that guides the industrial occupation of their territories and violates Mapuche ancestral rights; and the enormous changes in their ecosystem and the subsequent impact on the well-being of their communities. The authors analyze the contradiction between Mapuche epistemologies and the capitalist and positivist logic consecrated in the current Chilean Constitution. While the latter conceives of ecosystems as unlimited resources that can be exploited, the former connects health to the natural ecosystem and promotes nature's protection through the recognition of the rights of nature itself. Changes affecting the ecosystem have generated uncertainty and a lack of well-being, violating the right to full health. Moreover, many interviewees describe this colonization and neo-colonization as a severe loss and important trauma in their people's history. Throughout, they express their struggle to recover and validate their constitutional rights as well as their collective health.

The last two papers broaden right to health pedagogy and propose important theoretical developments for doing so, based on extensive work in global health in Latin America and Africa.

Luis Ortega, Michael Westerhaus, Amy Finnegan, Aarti Bhatt, Alex Olirus Owilli, Brian Turigye, and Youri Louis are part of EqualHealth, a transnational group of social medicine educators and practitioners who work in Uganda, Haiti, and the United States. In this paper, they reflect on their collective development of an integrated framework in human rights education, grounded in transformative pedagogies to foster dialogue between Latin American social medicine, collective health, and the framework of structural vulnerability.[20] They argue that transformative pedagogy should guide collaborative curricular design and evaluation oriented toward learner outcomes linked with social change. They propose pedagogical tools grounded in the dialogue between those critical and transformative pedagogies to actualize the human right to health.

Likewise, Fátima Rodríguez-Cuevas, Jimena Maza-Colli, Mariana Montaño-Sosa, Martha De Lourdes Arrieta-Canales, Patricia Aristizabal-Hoyos, Zeus Aranda, and Hugo Flores-Navarro from Compañeros En Salud, a Mexican organization related to Partners In Health, criticize the fact that most of the curricula in global health are developed and delivered in the Global North for students from high-income countries who in most cases will not end up working in global health. Considering this, their organization has created a human rights-based global health and social medicine curriculum adapted to the local setting of their rural region in Mexico. Alongside Farmer's standpoint, this curriculum expands the right to health, advocating for an integrative human rights approach in which social and economic rights are given the core relevance they deserve while also emphasizing civil and political rights. The right to health cannot be seen as an independent human right; it is interdependent on other economic and social rights, such as the rights to work, water, food, housing, education, and nondiscrimination.

Based on 10 years of experience, Rodrí-

guez-Cuevas et al.'s work underlines the importance of developing and implementing interdisciplinary curricula and emphasizes the importance of integration with communities. In their words:

> Compañeros En Salud aspires to establish more proximity with the communities in order to understand their perspectives and, in turn, improve the services and care they receive. Last but not least, we have learned that the joint construction of a knowledge paradigm, agreed-upon intervention criteria, and the promotion of shared values between the medical team and the community generates the possibility of communicating through a language that helps unify the members of each cohort.

Conclusion: Implications for a new global social medicine

This collection of papers building from the legacy of Paul Farmer shows us the possibilities that global social medicine practice and scholarship hold for the right to health. This globally diverse social medicine confronts North-South asymmetries while thinking and working toward racial justice and against coloniality. This will be a social medicine critical of the nation-state's role in reproducing power asymmetries, hierarchies, and exclusions. It will also be critical of that same nation-state's inability to protect its citizens' health in the face of the power of large corporations and distortions from neoliberal regimes. It will be a social medicine that responds to the concrete needs of individuals and collectives and, therefore, intimately connects with social movements and community processes. It will address racial justice in all its dimensions (including epistemological, institutional, and structural ones). The social medicine of the future will not be Eurocentric or Anglocentric; it will build its proposals and actions on the basis of the different ontologies, epistemologies, methodologies, and ethics that are at the heart of social movements, in critical dialogue with the best anti-hegemonic proposals of knowledge from around the world—including and moving far beyond Europe and Anglophone North America. This social medicine invites us to think in renewed ways about the right to health, including,

as Farmer teaches us, everything that allows and produces full health for all.

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Food Security as a Social Determinant of Health: Tackling Inequalities in Primary Health Care in Spain

MIREIA CAMPANERA, MERCÈ GASULL, AND MABEL GRACIA-ARNAIZ

Abstract

Food insecurity can be understood as a manifestation of health inequality and thus a deprivation of the right to health. This paper explores the strategies followed in primary health care centers in Spain to care for people struggling to regularly access healthy, safe, and sufficient food. Ethnographically based, our study analyzes, on the one hand, the resources available to primary health care teams to assess the social determinants of health and, on the other, the importance that professionals give to food in the diagnosis, treatment, and prevention of diseases related to inequality. Given that our study was carried out during the recent economic and health crises, the results show the difficulties faced by these centers in responding to constantly changing social needs. Budget cuts, a lack of specific or structural actions, and the invisibilization of particular expressions of inequality have proven challenging to the aim of providing integrated care capable of recognizing the environmental factors that condition patient health. In the case of food insecurity, our study found that there are no instruments in primary care centers to identify and therefore address this insecurity. We explore whether this is due mainly to the growing lack of means or more to the fact that the relationship between material living conditions, food, and health has been downplayed—and the responsibility of the health system in guaranteeing the right to food correspondingly diluted.

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Introduction

Decades ago, the 1978 Declaration of Alma-Ata focused on the responsibility of governments to provide health care for the entire population, emphasizing the importance of primary health care and its potential to cover 70% of health needs during the life cycle.[1] Years later, the World Health Organization (WHO) recognized that social, political, and economic conditions can make it extremely difficult for people to access health care and, consequently, for the right to health to be fulfilled.[2] Recognizing the impact of structural and intermediate determinants on health, WHO established guidelines on the social determinants of health that were to guide states in combating social inequalities.[3]

Despite health equity having gained priority within the European political agenda, Spain confronts specific obstacles to addressing social inequality in its health care system. The Ministry of Health developed a roadmap for moving toward health equity in 2015, but its proposed policies and interventions to reduce social inequalities have been repeatedly altered.[4] These difficulties have been exacerbated as a result of the cuts in health care spending following the economic recession of 2008 and the impact of COVID-19.[5] The hospital-centered and primary health care policies before the 2008 meltdown tended not to include goals or resources aimed at reducing inequality.[6] There were few examples of interventions that took inequality into account, and even fewer that included identifying and addressing food insecurity and its associated comorbidities.[7] It is well established that not having regular access to enough safe, healthy, and culturally appropriate food is related to obesity, hypertension and hyperlipidemia, diabetes, hypoglycemia, chronic kidney disease, and frailty in the elderly.[8] Food insecurity is an expression of social inequality that compromises the physical and emotional health of marginalized people, and therefore their right to health.[9]

Despite the fact that food security is fundamental to human dignity and the full enjoyment of human rights—and that Spain is a party to the International Covenant on Economic, Social and Cultural Rights, which protects the right to adequate food—recent administrations have not taken sufficient measures to ensure this right. On the contrary, the increase in food insecurity in the last decade, coinciding with the recent economic and health crises, makes this evident.[10]

This paper explores the strategies followed in primary health care centers (PCCs) in Catalonia, Spain, to provide care to people struggling to regularly access healthy, safe, and sufficient food. Ethnographically based, the study analyzes, on the one hand, the resources available to primary health care teams to assess the social determinants of health and, on the other, the importance that professionals give to food in the diagnosis, treatment, and prevention of diseases related to inequality. Recognizing that equity depends in part on the implementation of public health actions and social policies, we focus particularly on the type of dietary prescriptions and recommendations proposed to patients visiting these centers, examining whether they are an effective means of addressing the determinants of social inequalities in health.[11]

Since the study was carried out during the recent economic and health crises, the results show the difficulties faced by these centers in responding to continuously evolving social needs. Budget cuts, the lack of specific or structural actions, and the invisibilization of particular expressions of inequality are proving challenging to the aim of providing integrated care capable of recognizing the environmental factors that condition patient health. In the case of food insecurity, no tools were found in the PCCs to identify and thus address it. We explore whether this is due mainly to the growing lack of resources or more to the fact that the relationship between material living conditions, food, and health has been downplayed—and the responsibility of the health system in guaranteeing the right to food correspondingly diluted. The ultimate purpose of this paper is to suggest conceptual and practical changes that could contribute to making health equity a priority for all.

Materials and methods

This paper presents the results of research carried

out at the primary care level during two periods as part of different research projects, both focused on food security. The first studied the precarization of daily life due to the 2008 recession, and the second (which is ongoing) explores food insecurity among the elderly post-COVID-19.[12] We have selected primary health care as our focus because it is an essential sector that provides basic assets for the health of individuals and can monitor the extent of social determinants that are detrimental to a population's health.

In Spain, the health system is decentralized, with health management and policies mainly the responsibility of the different autonomous communities, such as Catalonia and Andalusia. Each autonomous community is divided into "health regions" (regiones sanitarias), which are in turn subdivided into "basic health areas" (áreas básicas de salud). Each health region has multiple teams of primary health care practitioners who serve in PCCs that provide basic medical care to all citizens at the local level.[13] Catalonia is the Spanish region where most of our fieldwork took place—specifically, in the cities of Reus and Tarragona, and the Barcelona and Ebre areas. We also did research in the Málaga area, within the Andalusia region (see Table 1). In this work, our informants consisted of 22 professionals from nine PCCs who worked in the areas of nursing, family practice, and social work. We selected those centers due to their location in neighborhoods with high levels of socioeconomic deprivation.[14]

Since primary health care staff are one of the groups closest to citizens when it comes to health care, these practitioners are key actors in this research. The practitioner selection process was conducted using the snowball technique, following some contacts from the research team at two PCCs who, in turn, put us in contact with staff working in other highly deprived areas. One center that was especially accessible to our research team was selected for an in-depth study, with nine interviews and participant observation conducted over seven months.

Our research techniques consisted of participant observation and semi-structured interviews.

Given their complementarity, these qualitative techniques are useful for collecting and analyzing health practitioners' narratives and for looking at subjective and institutional contexts as well as daily practices in primary health care. The interviews allowed us to gain deeper insights into the perceptions of primary health care practitioners about social inequalities, the social and health status of their patients, and their own professional performance.

All interviews lasted 60–90 minutes and were conducted in the clinics where the health care and social workers were active. The same script was used by eight members of our research team. Staff from different areas were interviewed given their relevance and suitability to the study: eight nurses (general and pediatric), nine family doctors, and five social workers, all of them women except for two family doctors. Most professionals had begun working before 2008. In addition to interviews, we conducted participant observation in the nine selected PCCs. At each PCC, the researcher took center-specific notes and collected information on the activities of the center and the social context of the neighborhood. After recording and transcription, we coded and processed the interviews using the ATLAS.ti qualitative data analysis software. Sixteen codes were selected to identify the main variables of analysis, contributing to the systematic development of category organization and thematic analysis (see Table 2). The most relevant codes were defined though a consensus meeting among all the researchers.

Our methodology also gave consideration to the importance of contrasting and complementing the practitioners' discourses with data from health surveys at the national and regional levels related to the 2006–2021 period—that is, going back to before the 2008 economic meltdown and including the COVID-19 pandemic. These surveys provide quantitative data on diseases broken down by gender, age, educational level, and social class. At the same time, we analyzed extensive documentation, including national and regional strategic health plans, reports and programs from the health care sector, and specific documentation for each center,

as well as specific tools such as social scales.

Results

Patients' social situation

When assessing the social and economic situation of patients, nurses and doctors use various methods. In the medical history of each patient, there is a section with a social-risk scale that allows health practitioners to describe those situations that they consider to be affecting their patient's health. This section contains six items on economic vulnerability, family context, housing conditions, and dependency status, but none on food security. Practitioners also have recourse to "Z codes," a list of labels that can be used to indicate social problems such as economic, job, or family insecurity, or gender violence.[15] Just two of the interviewees, who are family doctors, acknowledged using these codes occasionally, but they also stated that they

have access to a complete social history of the patient, compiled by social workers.

The clinical interview is the most commonly used means in medical and social settings for understanding a patient's context. According to practitioners, it is possible to gauge a patient's social situation by means of direct or indirect questions: for example, what kind of work they do, whom they live with, what ailments they suffer from, whether they struggle to make ends meet, how many meals they have a day, and what they ate the day before or earlier that same day. Doctors and nurses alike pointed out that for patients in a precarious situation, their health problems are just one more issue on top of a set of difficulties that they consider to be of a more serious nature because of their urgency.

While almost half of the practitioners interviewed reported being clearly interested in their patients' context and asking questions and listening to them, this does not necessarily mean that talking about these issues is a common practice or

TABLE 1. Interview data

No.	Gender	Professional role	Years of experience (at the time of interview)	Primary care center	City or area	Region	Fieldwork period
1	Female	Medical doctor	11	A	Reus	Catalonia	2018–2019
2	Female	Social worker	20	A and B			
3	Female	Pediatric nurse	14	C			
4	Female	Pediatric nurse	40	C			
5	Female	Nurse	24	D	Tarragona		
6	Female	Social worker	16	D			
7	Female	Social worker	25	E			
8	Female	Medical doctor	12	E			
9	Female	Nurse	16	E			
10	Female	Medical doctor	20	F			
11	Female	Medical doctor	12	F			
12	Male	Medical doctor	17	F			
13	Male	Medical doctor	6	F			
14	Female	Medical doctor	13	F			
15	Female	Medical doctor	34	F			
16	Female	Social worker	7	F			
17	Female	Nurse	9	F			
18	Female	Pediatric nurse	13	F			
19	Female	Nurse	20	G	Barcelona area		
20	Female	Medical doctor	9	H	Ebre area		2021
21	Female	Nurse	7	H			
22	Female	Social worker	15	J	Málaga area	Andalusia	

that informs practitioners' interventions and prescriptions. Most nurses consulted reported feeling awkward when asking about these issues, not least because of the embarrassment that some patients experience when talking about "their hardship" during their clinical appointment. Patients often show reluctance to talk about their difficulties in accessing food and their loss of purchasing power, as well as their need for social assistance. Some practitioners try to compensate for the limited time available to them for individual visits by working toward a more lasting relationship and building trust over the long term. This allows them to learn more about the lives of those patients who are willing to share their experiences. However, the professionals interviewed explained that the COVID-19 pandemic significantly transformed patient-practitioner contact—which was reduced to phone calls during lockdown—and made it more difficult to detect situations of deprivation. With home visits, often made by nurses in very unique cases of dependence, it is easier to see if a person is struggling with their finances. At home, practitioners can directly observe what resources for hygiene and personal care are available to the patient, if they suffer mobility restrictions that keep them from doing their own shopping, whether they can cook, whether they live alone, and what they eat; practitioners can even detect cases of malnutrition that might otherwise remain unnoticed. Of all the professionals interviewed, only one nurse

considered that the socioeconomic situation of patients has no impact on their health and that there is therefore no need to inquire about it.

Embodying uncertainty

Most practitioners said that the economic recession of 2008 led to a worsening health status among the most disadvantaged layers of society. Respondents were asked about the effects of growing uncertainties. "There are social problems that lead to health issues," explained a 64-year-old nurse. Mental health problems were the most cited. They refer to an increase in despondency, anxiety, and depression, and also to the way in which unemployment, job insecurity, and economic instability all damage health. All professionals interviewed in 2021 pointed to an increase in solitude, isolation, fear, and emotional suffering in their older patients.

Health care professionals also associated various insecurities with obesity, cardiovascular risk, diabetes, smoking, and increased alcohol consumption. Although few reported examples of how social inequalities are reflected in the health of their patients, it was common for them to relate the emotional alterations that come with job instability to weight gain: "Anxiety always leads to excess weight, in the cases we see here. When anxiety subsides, they start to lose weight; they gain weight partly because of the medication and partly because they move less. Anxiety itself makes them increase the amounts they eat" (P27, Tarragona). Practitioners

TABLE 2. Coding scheme

Thematic areas	Analytical categories
Social and living conditions of patients	Social condition
	Social inequality
	Food aid
Health status and life insecurity	Diseases related to life insecurity
	Overweight and obesity
	Nutritional issues
Interventions by PCCs	Social knowledge tools
	Health care intervention
	Community intervention
	Food intervention
	Hurdles to interventions
COVID-19	Changes and continuities in health and food

cannot easily separate mental health from other health issues, especially when "suffering people say that they eat as a way to find relief from anxiety and get immediate gratification" (P27, Tarragona). A doctor treating a family that had been hard hit by the economic meltdown saw a link between the continuum of employment and emotional setbacks experienced by family members and their mental health: work incapacitation and psychic dementia in the mother, job insecurity and suspected cancer in the father, and domestic violence by the mother on her daughter.

One family doctor explained that, in the peak years of the recession, she received work incapacity applications on a weekly basis. She associated this fact with worsening working and economic conditions; indeed, the Catalan Health Survey reported an increase in incapacity for work during that period of crisis, particularly among people with primary education only (complete or incomplete).[16]

Other health issues related to social inequality are chronic diseases and malnutrition. While just a few cases of undernourishment have been detected in primary health care appointments, obesity and overweight, as well as diabetes, are often seen as the result of precarious social situations. Health care workers explained that undernourishment occurs in elderly people who live alone, have few resources, and do not follow the recommended diet, especially in families who depend on food donations (with a very high incidence among non-European Union citizens) and in extended family households whose only income is a retirement pension. People over 75 are usually tested for undernourishment by health professionals, often with positive results. These are people who eat little meat, fish, and dairy products; many are care-dependent or else cook only with difficulty and go shopping irregularly. The practitioners we interviewed did not report applying these tests to people at risk of poverty.

Food practices in medical consultations: Recommendations, habits, and individual responsibility

Nursing professionals are the ones who intervene most in the food sphere, issuing recommendations based on each patient's situation. They advise on food types, amounts, products to avoid or eat sparingly (e.g., sweetened or ultra-processed foods, pastries), mealtimes, and number of daily meals. One of the most commonly used techniques is the "dish method," where patients are instructed that a meal needs to contain 50% vegetables, 25% carbohydrates, and 25% protein; this also entails an explanation about the different food groups. Nurses also suggest physical activity and modified shopping habits, and they perform checks on weight. When they detect diabetes, excess weight, or obesity, they also suggest specific diets. According to one nurse, it is a matter of "sorting out their diet a bit … so they know what to eat and what to say no to, what shouldn't enter the house and what shouldn't be bought" (P12, Tarragona). In general, they suggest eating five times a day, including five pieces of fruit and vegetables, and reducing the intake of hyper-caloric foods.

All of these are interventions focused on individual behavior. Many physicians and nurses pointed out the difficulty of effecting change in eating habits or of conducting follow-up due to the short visiting time they are accorded for each patient. Nurses noted that their advice usually falls on deaf ears because "people already know what they should do, but fail to do it" (P12, Tarragona). Those professionals with patients who try to introduce healthier eating habits say that barely 30% of their patients manage to do so. These are usually younger people or individuals with health problems that can be aggravated (e.g., diabetes and high blood pressure), and therefore they see the need for a change in habits. They tend to be people motivated to make changes, and people with sufficient economic and emotional resources for such a transformation, who also find support in their social environment.

About half of the professionals considered that community intervention is necessary to change the population's eating practices, although they also pointed out that some colleagues refuse to implement a model that requires leaving their offices, citing a lack of time and incentives. One nurse participated in a "Health at School" program by conducting workshops on healthy eating in

schools, where similar recommendations adapted for children were made. Another nurse collaborated with teachers in the community project Dynamis, involving 12- to 14-year-old students, their families, and the school, and promoting extracurricular physical activity and healthy eating. This program was endorsed by the Health Department, and a nurse considered it more effective than the "10-minute talk in consultation room" (P5, Tarragona). In most cases, practitioners' assessment of the effects of these actions mentioned only short-term change; in other cases, there was no consistent monitoring or assessment of the program, and therefore its impact is not known.

In cases of patients with a diagnosis of obesity or diabetes, all practitioners acknowledged having treated people who cannot follow the recommended diet due to financial difficulty in accessing a varied and nutritionally adequate diet. After one doctor prescribed a proper diet to treat diabetes, her patient replied that he could hardly follow it because "he only ate what he was given at the Red Cross" (P1, Tarragona). The organization provides non-perishable food packages that only occasionally include fresh fruit, vegetables, meat, and fish. In cases where food insecurity is detected, practitioners refer the patient to charities (e.g., Red Cross, Caritas) or social services. Referral to social services and monitoring of the patient is done by the center's social worker in coordination with doctors. There is no specific monitoring of food consumption, though practitioners acknowledged that their patients receive canned, ultra-processed, and ready-to-eat food. During the 2020 lockdown, two PCC professionals, in coordination with the local council, charities, and social movements, collaborated in a food security initiative that organized home deliveries of food to the elderly.

When asked whether they had detected changes in the types of food consumed by their patients and the possible causes, professionals pointed to a high intake of sugary, high-fat, and pre-cooked products because they are more affordable. They argued that "today, people cook less and eat badly due to an excess of certain ingredients or to their quality" (P6, Reus). They also observed a widespread and excessive use of low-nutrient ingredients. In fact, the Spanish Food Consumption Panel and the National Health Survey confirm a decline in fresh fruit, milk, meat, and fish consumption, and an increase in processed foods.[17] Both WHO and Spain's Strategy for Nutrition, Physical Activity and the Prevention of Obesity state that the food industry has played a role in making "unhealthy" food more accessible, and they call for a reduction in the fat, sugar, and salt content in food and for the regulation of the advertising of such food.[18] Only two nurses identified the food industry and health authorities as responsible for this easy access to unhealthy food. Regarding the food practices of their patients, one doctor highlighted the importance that sweet foods (e.g., pastries, cakes, and candies) have in celebrations and hospitality practices in certain cultures. Another professional commented that the appreciation of the corpulent body as healthy and beautiful among Moroccan women hinders any medical intervention aimed at reducing overweight and obesity in this community.

In general, most professionals recognized their limitations in trying to reduce health inequalities. One way to tackle them, suggested some nurses, would be to increase community interventions. These practitioners noted that patients are often reluctant to follow medical-nutritional prescriptions because they see them as part of an outdated and repetitive monologue; the practitioners thus proposed increasing the actions carried out *with* and *from* the community through a participatory process that considers the particular needs of the community. But other practitioners were skeptical of the effectiveness of community interventions; they emphasized the individual responsibility of patients, judging their habits to be not so much a result of their living conditions but of inappropriate behavior, or unwillingness or lack of interest in following the rules: "It's hard for them to diet, it's hard for them to exercise, it's hard for them to do anything … Aw! You have to lose weight. Can't you see you're too fat?" (P14, Reus). This divergence in practitioners' views is then reflected in practitioners' greater or lesser involvement in community actions.

Intervention in community health

Training in community intervention for health personnel can be an important tool for tackling social inequality, given that it involves a shift in intervention strategy and in the practitioner-patient relationship. According to a nurse who works in social diagnosis, "It's not about what you think people need; what I have learnt from the community is that it is about being there and letting them express their demands … and finding out what it is they need the most" (P12, Tarragona). This training process can be seen as one of co-learning and adoption of diagnostic and social intervention tools that can produce results in the medium term.

One of these centers studied in our research has a multidisciplinary team that undertakes various community-based initiatives; one such initiative was the conducting of a social diagnosis of the neighborhood in collaboration with primary health care workers, the city council, the community center, and Catalonia's Public Health Agency. The center shared the results in a video posted on YouTube.

Another center has been implementing the Catalan government's COMSalut community program—which seeks to reduce social inequalities as they relate to health—since 2017. Every month, the entire primary health care team is provided with social resources to be prescribed to their patients, in the same way as prescription drugs. These resources include social, recreational, and sports activities or programs, as well as other services such as addiction care and services for women. Though the COMSalut project started in 2015, only 16 of the 434 PCCs in Catalonia are involved.

In a third center, the nursing area conducts workshops on nutrition in secondary schools within the framework of the Health at School program. Its objective is to improve adolescent health through health promotion actions, such as *consulta oberta* (literally "open consultation") whereby nursing staff are regularly sent out to schools. One nurse explained that this action is sometimes seen as an imposition by some schools, hindering positive collaboration.

The Catalonia Health Department has implemented other community health programs. A prominent one was "Health in the Neighborhood," created in 2005; however, the actions and programs that were in place at the time of our research mainly fall under the AUPA Network, formed by working groups providing support and training to primary health care and public health professionals in each health district. In the Tarragona area, only nine primary health care teams are part of this network. It is an initiative that originated from the Interdepartmental Plan for Public Health, in line with WHO's recommendations to promote health in all areas and policies.[19]

Discussion

The current Spanish strategic framework and recent Catalan health plans recognize the impact of the 2008 recession on the living conditions of the most vulnerable. The latest health plan also points out the negative consequences of the COVID-19 pandemic.[20] While these policies are presented as being inclusive, the scarce resources available at PCCs allow for only a limited integration of the social determinants of health approach, which hinders progress in reducing inequalities.[21] The severe cuts in funding during the last decade, the failure to implement effective specific or structural measures, and the lack of recognition of the specific effects of social inequality—such as food insecurity—have reduced the overall system's ability to respond to citizens' health needs. The social determinants of health are recognized but not addressed in a systematic and community-based form, either within or outside the health sector. This inevitably hinders the exercise of the rights to health and to food. The COVID-19 pandemic has worsened this situation by forcing a sharp shift in the organization of primary care that focuses on the pandemic while neglecting other health services.[22] Moreover, these services, when provided, are approached from a merely biomedical stance. Although professionals have information about the social situation of their patients, this does not necessarily translate into a

practice focused on mitigating the consequences of inequality.

Most of the primary health care professionals participating in this research are aware of the importance of the social determinants of health; however, their views on the effects of increasing life uncertainties in health are divergent. The majority recognize the lack of tools to improve health equity but believe that it is not in their hands to solve it. A minority signal the need to design strategies that would allow them to intervene in the social sphere, along with other non-health sectors, in order to deal with health problems. We found that those professionals who are motivated to carry out community activities do so more of their own volition than at the instigation of the health system. They consider the instruments available to them to address the social determinants of health to be clearly insufficient. As is the case in other countries, a lack of time, training, and incentives are added difficulties for overburdened professionals after decades of underfunding, further compounded by budget cuts after 2008, and especially after tackling the COVID-19 pandemic, which interrupted community intervention.[23] As WHO has pointed out, many health professionals have experienced burnout following the pandemic, resulting in their own physical and emotional health being compromised.[24]

However, the lack of training in social determinants of health and a structural competency approach explains this divergence in understanding and tackling health inequalities, specifically food insecurity. As Jonathan Meltz and Helena Hansen propose, training in structural competency requires gaining competences in recognizing the structures that shape medical interaction and understanding "socially structured patterns of disease across population groups and economies in ways that point to structural agendas for political and economic change."[25] They also recommend considering how complex cultural structures produce inequalities and barriers to inclusion. Finally, such an approach would require practitioners to be trained in discerning how issues defined clinically as symptoms, attitudes, or diseases also represent the implications of social and political structures.[26]

The response from primary health care to health problems resulting from increasing insecurity in the population's living conditions has been vague and feeble. The primary care model in Spain was and still is a disease-oriented model, rather than being person and community centered. This is due to practical and bureaucratic reasons: poor allocation of resources has always made it impossible for PCC practitioners to devote time to education, health promotion, or community health tasks, other than in pilot programs such as those described above. Our results reveal that the largest barrier seems to be the organization of primary care itself, as well as its coordination with other social and public services. This is a burden that some experts say comes directly from the split between health services and social services during the 1980s.[27]

The health system alone cannot remove health inequalities, but it must do its part to reduce them. A comprehensive approach to social inequalities in health is needed from the perspective of the social determinants of health. The health system is just one more determinant, so its contribution to equity is necessarily limited, if essential.[28] Before the COVID-19 pandemic, the social determinants of health approach in Catalonia was rare at the first level of health care, and the social and community perspective had not been widely assimilated into primary health care, except for a few pilots. In Spain more generally, the Ministry of Health's plan to reduce inequalities has not been implemented to any significant extent. No substantial progress has been made in citizen participation or adequate service provision for the most vulnerable groups.[29] In this country, the COVID-19 pandemic stopped all community nutritional health programs for almost two years. However, other community initiatives emerged during lockdown to mitigate food access difficulties.[30] According to the Food and Agriculture Organization, the number of Spaniards in a situation of food insecurity rose from 600,000 in 2019 to 700,000 in 2020.[31] Although there are no official reports on food insecurity in Spain, some studies indicate that women experience greater forms of food insecurity, as they have to mobilize all the resources available in order to minimize

the impact of precarization on their households.[32] At the global level, there is little implementation of the WHO proposal on the social determinants of health, and a lack of specific actions stemming from the Declaration of Astana or the human rights approach.[33]

One of the limitations reported by primary health care personnel is their limited capacity to have an impact on situations of social suffering, understood as the distress resulting from unemployment or precarious employment, and difficulties in accessing decent housing or healthy food, among other situations. In the case of food insecurity, what is surprising is that despite its being associated with poorer health outcomes in routinely managed conditions such as obesity and chronic diseases, PCCs do not use specific instruments to identify it.[34] Nor do they have any indicators to analyze and determine individual or household levels of food insecurity. In fact, food insecurity is not mentioned as a problem to be solved in any public health plan in Spain or Catalonia. The Catalan government designed a food safety plan in order to address the social determinants of health in 2021 but did not ensure regular access to adequate food in times of increasing poverty.[35] In fact, a WHO report pointed out that food security has been further compromised for marginalized communities worldwide due to COVID-19, and the new health policy did not tackle that.[36]

This is partly a consequence of using a conceptual framework that reduces food to mere individual behaviors. As far as food practices are concerned, health interventions are limited to providing healthy eating guidelines within a clinical-therapeutic framework. The activities proposed to patients are still focused on self-control and responsibility, as if the individuals' food choices and practices were not determined partly by their social and family structures.[37] Food is thus decontextualized from the social environment, stripped of everything in a way that ultimately hinders regular access to nutritionally and culturally adequate eating practices. This reduces practitioners' proposals to a set of generic recommendations on healthy

eating and contributes to ignoring food insecurity both as a health and as a political issue.

Three specific findings from our research stand out in terms of increasing our understanding of food insecurity as a manifestation of health inequality and the way it is addressed in primary care.

First, we observed a difficulty among practitioners, due to a lack of specific or adequate tools, in detecting food insecurity. Long-term, trusting doctor-patient conversations and home visits have significant potential but are neither systematically nor widely developed. We wonder to what extent this lack of intervention is due to inadequate means and resources in the health care centers and to what extent it stems from a downplaying of the relationship between material living conditions, food, and health, leading to a dilution of the health system's responsibility.

Second, Catalonia's current and previous health plans recommend a "Mediterranean" diet—in other words, lots of vegetables—and this is the message that nurses transmit.[38] But in cases where food insecurity is detected—in Spain as in other countries—the patient is usually referred to charities or social services, which donate consignments of non-perishable, canned, processed, and ready-to-eat food.[39] Ultra-processed products are very common in the daily diet of people living in precarious situations, in part because these foods are often cheaper.[40] This makes the recommended healthy diet, based on the variety, quality, and quantity of certain ingredients, difficult to follow.[41] Moreover, with the COVID-19 crisis, the demand for food aid tripled in Spain in 2020, so the public sector response to this problem continues to revolve around emergency aid, or "discarded food for hungry people."[42]

Third, public policies on health, food, and social welfare are failing to guarantee the right to food or to prove effective in enabling the most impoverished populations to feed themselves with autonomy and dignity in times of increasing poverty.[43] Health, social, and food policies must embrace coordinated actions to mitigate inequality and must be designed, systematized, and evaluated

with the participation of vulnerable social groups, health professionals, and social agents.[44] In this area, the Spanish state has identified shortcomings that have not been resolved for more than a decade yet require urgent solutions.[45] Our research shows the importance of analyzing food insecurity in detail at the primary level of health care, given that it is not only an indicator of inequality in itself but also at the root of preventable health problems. If healthy, safe, and sufficient food is not assured, the right to health is compromised.

Ethics approval

The results discussed in this paper are part of a research project.[47] The funding agency in 2016 did not request a specific evaluation by an ethical committee, so our research was not submitted for an ethical evaluation.

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From Apathy to Structural Competency and the Right to Health: An Institutional Ethnography of a Maternal and Child Wellness Center

MARGARET MARY DOWNEY AND ARIANA THOMPSON-LASTAD

Abstract

Given the persistence of health inequities in the United States, scholars and health professionals alike have turned to the social determinants of health (SDH) framework to understand the overlapping factors that produce and shape these inequities. However, there is scant empirical literature on how frontline health and social service workers perceive and apply the SDH framework, or related movements such as the right to health, in their daily practice. Our study seeks to bridge this gap by applying constructs from the *sociological imagination* and *structural competency* (an emerging paradigm in health professions' education) to understand the perspectives and experiences of social work case managers, community health workers, legal advocates, and mental health counselors at a maternal and child health center in a large US city. This frontline workforce displayed strong sociological imagination, elements of structural competency, and engagement with the principles of the right to health. Workers shared reflections on the SDH framework in ways that signaled promising opportunities for frontline workers to link with the global movement for the right to health. We offer a novel approach to understanding the relationships between frontline worker perspectives on and experiences with the SDH, sociological imagination, structural competency, and the right to health.

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Introduction

Health inequities are avoidable and unjust differences in injury, disease, violence, and opportunities to experience optimal health. The social determinants of health (SDH) are a framework to understand the overlapping factors that produce these inequities. The World Health Organization defines the SDH as "the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life."[1] Frontline health and social service workers play a pivotal role in shaping what the SDH framework becomes in daily practice. However, most extant scholarship on SDH has undertheorized the role and experiences of the frontline workers who are tasked with bringing this framework to life.[2] Moreover, many of the SDH framework's leading proponents have expressed concern over a narrow or reductive uptake of their original message around the conditions shaping health status, citing research and practice that emphasizes "lifestyle" factors such as exercise or diet at the expense of social and economic rights.[3] Understanding frontline workers' perceptions of and experiences with the SDH framework is critical to addressing health inequities. Such understanding will inform the development of trainings, programs, policy, and organizing efforts toward the right to health. Frontline workers have a crucial role in the broader movement for the right to health because they witness, experience, and may be complicit in the embodiment of injustice.

Drawing from an institutional ethnography of frontline workers in a maternal and child wellness center in a large US city, the present study examines frontline workers' perspectives on the etiology and origins of the interlocking health and social inequities within which they and their clients live. We seek to inform the development of structural competency (an emerging health education paradigm) and link to movements for a right to health. We first turn to C. Wright Mills's concept of "sociological imagination" to understand workers' perspectives on the SDH framework and its implementation.[4] This paper argues that sociological imagination is necessary for the development of structural competency and that structural competency and the

right to health are complementary frameworks that should inform each other.

Finally, we examine how previous scholarship on social and economic rights and the right to health might inform frontline worker perspectives on health inequities. Those who fight against health inequities may vacillate between apathy, burnout, sociological imagination, and structural competency during their engagement with the right to health. We outline how health as a human right is an animating vision to guide the shift from apathy to structural competency. We also discuss how engaging with the framework of human rights offers workers opportunities for allyship and solidarity in a global project for the right to health.

Background

Maternal health inequities in the United States

Maternal health inequities are a persistent, devastating public health problem in the United States. Black and Indigenous people and low-income people face poorer outcomes across nearly every metric of pregnancy and postpartum health.[5] The United States has the highest maternal mortality rate among industrialized nations, with 23.8 deaths per 100,000 live births, most of which are classified as preventable.[6] Black and Native American women are three to four times more likely than white women to die due to pregnancy-related conditions.[7] Socioeconomic stratification alone cannot explain maternal health inequities.[8] Research shows that experiencing racism throughout the life course contributes to a "weathering" impact that produces physiological harms for women of color.[9] These inequities reflect the persistence of structural racism and other social and structural conditions that are often overlooked or obscured in health services.

Sociological imagination

Developed by Mills, *sociological imagination* is the capacity to step outside of one's own routines, habits, and personal beliefs; understand individual experiences as part of a larger societal whole; and distinguish between "troubles" (personal dilemmas) and broader "issues." Issues are public

problems that may be experienced individually but are contingent on imbricated institutional, structural, and historical forces beyond the control of any one person. Mills argues that the absence of sociological imagination leads to individual and collective apathy, expressed as a dismissal of the social nature of crises and injustices. Apathy may mean pity or regret at the misfortune of others, yet failure to consider the social and structural causes of such misfortune. Individuals and whole societies may become accustomed to inequities even while agreeing that such inequities are objectionable.

We view Mills's "apathy" as related to the concept of "burnout" so prominent in health and social service research.[10] Apathy and burnout are common challenges in the health professions and often surface in undervalued, under-resourced settings that serve populations most impacted by health inequities.[11] Expressed in part as a cynicism, detachment, and loss of commitment to improving patients' lives, we understand burnout as potentially correlated with apathy as it emerges in health care settings. One may of course exist without the other.

Burnout may persist among health care workers who are deeply invested in recognizing social determinants and detach because of their frustration when they feel they cannot solve social problems (i.e., burnout but no apathy). Other health care workers may be committed to and satisfied with individual patient care but be indifferent to inequities (i.e., apathy but no burnout). Recent scholarship on the sociological imagination suggests that approaching poor health outcomes as individually embodied and structurally determined may help prevent and address burnout among health care workers. Other research on burnout has identified the need for institutional and structural change to support the well-being of health care workers and their patients alike.[12]

Perspectives on the social determinants of health framework

A growing body of empirical literature examines the perspectives of physicians, nurses, and social workers on SDH.[13] This work suggests that knowledge of and support for engaging SDH in these

FIGURE 1. The Dahlgren and Whitehead social determinants of health model
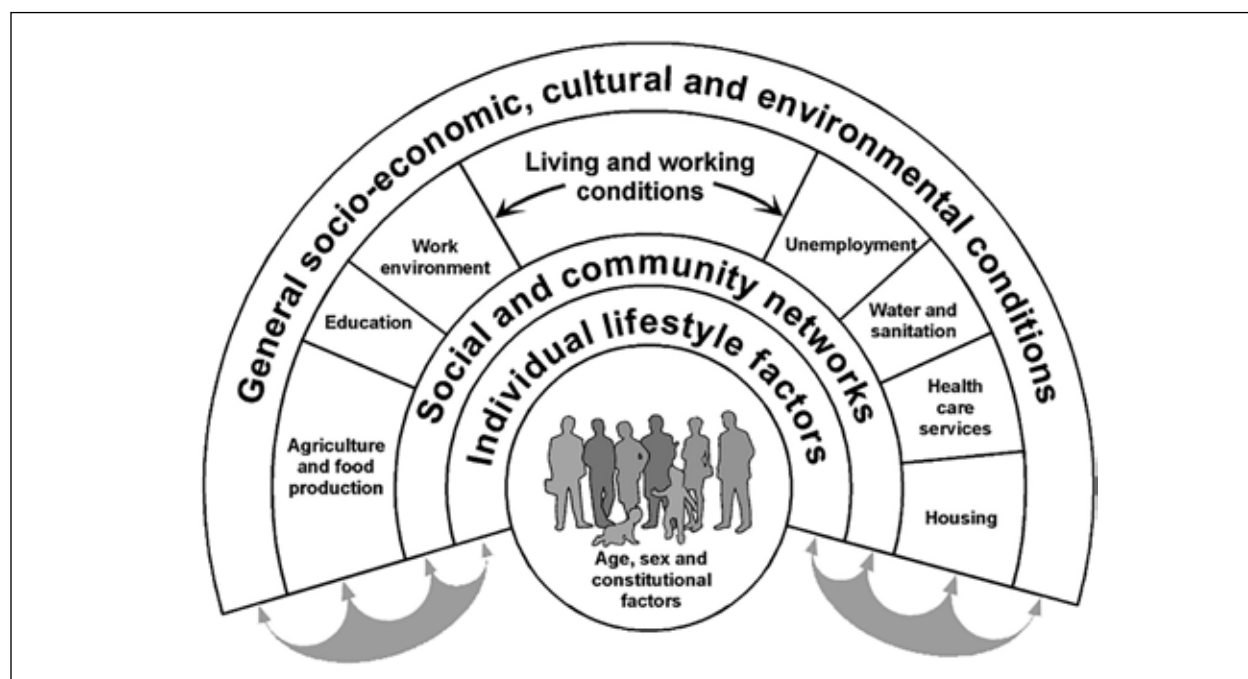
Source: G. Dahlgren and M. Whitehead, "The Dahlgren-Whitehead Model of Health Determinants: 30 Years on and Still Chasing Rainbows," *Public Health* 199 (2021).

professions is uneven, even for social workers (who ostensibly receive more training on social inequality than other health care workers).[14] There is little empirical research on other frontline worker perspectives (e.g., case managers, community health workers, health educators) on SDH. Our analysis attempts to fill these gaps in the literature.

Structural competency

Despite decades of research on SDH, health care workers typically receive minimal training on upstream factors.[15] Physician-anthropologists Jonathan Metzl and Helena Hansen have developed *structural competency* as a medical education framework to train clinicians in understanding how social structures inequitably shape individual and community health, and in working to change these structures (for Metzl and Hansen, examples include zoning laws, economic systems, schools, and courts).[16] Structural competency includes five intersecting skill sets: (1) recognizing the structures that shape clinical interactions, (2) developing an extra-clinical language of structure, (3) rearticulating "cultural" presentations in structural terms, (4) observing and imagining structural intervention, and (5) developing structural humility.[17] As noted by Joshua Neff et al., structural competency emphasizes "the structural determinants of the social determinants of health."[18] Thus, poverty (a well-documented social determinant of health) is determined by structures such as policies, economic systems, and social hierarchies (e.g., racism; see Figure 2). Since its inception, structural competency has been embraced by other professions, including nursing, social work, and psychology.[19]

Structural competency provides a framework to address health and health care inequities, as well as health care working conditions, by acting collectively—with colleagues, patients, and clients—to challenge unjust structures and institutions. Here, structural competency fills another important gap in the SDH framework. Though a powerful tool to describe patterns of inequity, the SDH framework does not define approaches to systems change or to combatting the "highly advanced knowledge of the biological impacts of lived environments alongside relatively undertheorized analyses of the environments themselves."[20] A sociological imagination allows people to imagine systems, broadly speaking. Structural competency is about understanding inequity *and* actively working toward structural change. Structural competency rests on the foundation set by sociological imagination and SDH while moving health care into proactive, collaborative strategies at the sociopolitical level and providing more patient-centered care at the individual level.

FIGURE 2. Structural determinants of the social determinants of health
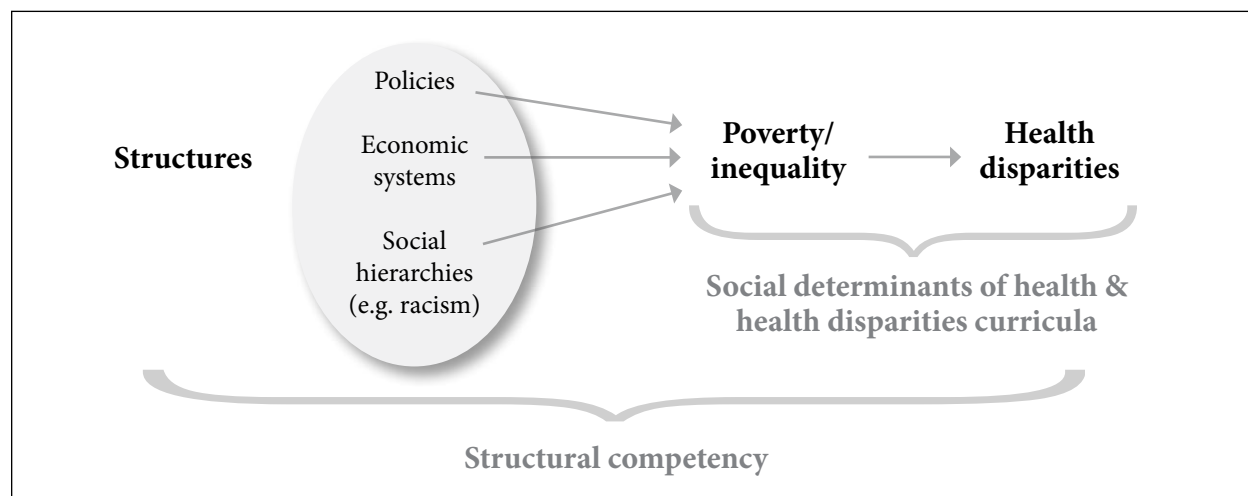
Source: J. Neff, S. M. Holmes, K. R. Knight, et al., "Structural Competency: Curriculum for Medical Students, Residents, and Interprofessional Teams on the Structural Factors That Produce Health Disparities," *MedEdPORTAL* (2020).

The right to health

The right to health is among the basic social and economic rights and encompasses both the right to health and health *care* for individuals and the right to public health, broadly defined.[21] While other concepts discussed in this paper (sociological imagination, SDH, and structural competency) were developed primarily by scholars in the United States and Western Europe, leading advocates and scholars of the right to health are based in Africa, Latin America, and the Caribbean, among other regions.[22] Engaging in the right to health movement situates local work to eliminate health inequities amidst a broad, visionary, transnational project. It gives frontline workers something to work *for* as part of broader organizing with the right to health movement. In a US context, it also serves as a corrective to the imperialist nature of some human rights work, where the United States and Western Europe claim moral supremacy, police other societies, and ignore violations of social and economic rights in our own countries.[23] Moreover, the right to health is a legal term, codified in international law and United Nations conventions ratified by most countries. In this paper, we analyze data from an institutional ethnography using SDH, structural competency, and right to health frameworks together in order to illuminate the ways in which frontline workers enact these frameworks in their day-to-day practice. We argue that independently, each framework is necessary but insufficient to understand and further motivate frontline workers' engagement with health inequities.

Methods

Institutional ethnography

This study employs institutional ethnography—a social science research method in which researchers embed with participants in their daily lives and routines.[24] Institutional ethnography investigates contested issues in the sociopolitical world through the experiences of participants whose lives are shaped by institutional forces (e.g., health policy, social welfare programs), such as frontline health and social service workers. Institutional ethnography was developed by sociologist Dorothy Smith to enhance social research's capacity to deal with everyday problems, knowledge, and relationships that are mediated through institutions. It has been extensively used in health care settings to investigate how nurses, social workers, and other professionalized groups experience everyday life.[25] Compared to other ethnographic methods, institutional ethnography pays particular attention to the role of text, making it an ideal methodology to study health and social service settings that rely on written communication to create, share, and reinforce authoritative knowledge.

The field site

Family Center is a 30-year-old nonprofit maternal and child wellness center located in a large city on the US West Coast. Since its inception, it has addressed the social determinants of the region's maternal and child health inequities. Family Center has approximately 100 full-time employees. More than half of its workers come from a community health worker program that recruits staff from former clients (primarily poor and working-class Latina and Black women). The current study began by focusing on the center's Health Team, which frequently receives referrals from local biomedical institutions (e.g., hospitals and clinics) and addresses what are traditionally understood as biomedical issues, such as prenatal and postpartum health, contraceptive use, and breastfeeding initiation, as well as financial, housing, food, and educational needs for pregnant and postpartum clients.

Reflexivity

Both authors are facilitators with the Structural Competency Working Group, a network of health care workers, patients, and social scientists who provide workshops and consultation on structural competency to health care workers and trainees, policy makers, and health professions faculty. These roles enhance our ability to interpret the data in relation to structural competency's core concepts. It also may lead us to overly rely on structural competency as an analytic frame. Our distinct professional backgrounds and shared

personal backgrounds also influenced our analysis. In the tradition of critical, post-structuralist ethnographers, we harnessed our social positions as data.[26] We are both middle-class white women with experience working in safety-net health care institutions. The first author is a former birth and abortion doula, social worker, and social welfare scholar, while the second author has given birth to two children, has worked as a health educator in the US health care safety net for five years, and is a medical sociologist.

The first author, as the researcher in the field, negotiated several relationships with participants and the research questions. Her identity as a white, middle-class social worker who moved to the region during a wave of gentrification perpetuated by similarly situated professionals may have influenced the way participants spoke about the economic and racial inequities they observe and experience. Her identities may have positioned her as an outsider. On the other hand, her health and social service-related training may have positioned her as an insider, facilitating access within Family Center.

Data collection

The first author spent nine months (three days per week) conducting fieldwork at Family Center, primarily with the Health Team. Her activities included clerical work, escorting clients to appointments, and preparing tea and leading doula demonstrations for weekly prenatal education classes. She attended staff meetings and trainings weekly. She also attended activities outside of the agency, such as colloquia at the local teaching hospital where Family Center staff were invited to brainstorm strategies to address health inequities. Early on in participant observation, she noted that while text on the city's Department of Public Health website and presentations used the SDH framework to describe Family Center's work, no frontline workers ever used the framework to describe their work. In the case of the Department of Public Health, the Dahlgren and Whitehead model was cited to describe Family Center. Manuscripts in development from this ethnography report more specifically on findings from participant observation.

Participant observation assisted the researcher in identifying relevant participants for semi-structured interviews, specifically those who worked most closely with clients on health and health care needs. There were 21 interviewees in total, including social work case managers, health counselors, health educators, community health workers, and a member of Family Center's executive team who supervised all frontline workers. All quotations are from semi-structured interviews. Throughout informal interviews during participant observation, all participants endorsed the relevance of social determinants in creating health and health care inequities, which motivated the interview protocol development. A purposive sampling approach was utilized. Interviews were conducted in person at a mutually agreed-on location within Family Center and averaged 67 minutes in length. Participants received a US$25 gift card. The semi-structured interview guide probed for daily routines and practices concerning client care, collaboration practices, and explanations for health inequities (e.g., "What makes it hard for some clients to be healthy?"). Perspectives on the SDH framework were elicited at the close of interviews, when participants were shown an image of Dahlgren and Whitehead's model and asked to describe it. This model was chosen because the Department of Public Health uses it to describe Family Center's work, because it is widely cited in public health literature generally, and because it balances breadth and depth with visual clarity.

Analysis

Data analyzed for this paper include field notes, interview transcripts, and agency documents. The first author repeatedly read all data to achieve immersion. She then combined *a priori* codes with codes derived inductively through a close reading of the transcripts.[27] She analyzed texts that were widely discussed within the center (e.g., annual reports) as well as those texts generated by authors or organizations outside of the center (e.g., Department of Housing policies). Next, directed and conventional content analysis were employed.[28]

For directed content analysis, terms from the Dahlgren and Whitehead model (e.g., "living and

FIGURE 3. The sociological imagination, structural competency, and the right to health

* A lack of curiosity as to the historical and contextual roots of public issues
* A dismissal and cynicism of the social nature of crises and injustices such as health inequities

A "high degree of emotional exhaustion and depersonalization (i.e., cynicism) and a low sense of personal accomplishment"† systemically produced by working in distressing environments that strain health care workers' physical, emotional, and psychological well-being and impede patient care.

• The capacity to step outside of one's own habits and routines to understand one's immediate experiences as part of larger social processes and structures.
• The ability to interpret one's own and others' actions as both influencing and influenced by social context.

Sociological imagination

Apathy

The right to health

Burnout

Structural competency

• The right to a "standard of living adequate for the health and well-being of [oneself] and of [one's] family,"* including the right to the social and economic resources and health care needed to promote and preserve this health and well-being.

• The trained ability of health care workers to understand and analyze how symptoms, clinical problems, diseases, relationships with patients, populations, and health systems are shaped by social structures such as policy, economic systems, and social hierarchies.
• The capacity to imagine and intervene in the structural factors producing health inequities, as well as provide direct client/patient care.

* Universal Declaration of Human Rights, G.A. Res. 217A (III) (1948), art. 25.
† National Academy of Medicine, "Clinician Well-Being," https://nam.edu/initiatives/clinician-resilience-and-well-being/.

working conditions: housing") served as *a priori* directed codes and were applied to interview transcripts, agency texts, and field notes. Conventional content analysis was applied to the same data to achieve inductive category development whereby data were read line by line to capture emergent codes and subcodes (e.g., "origin of health inequity"). Interview transcripts, agency documents, and field notes were then coded in Microsoft Word and subsequently organized into a matrix.[29] For subsequent analysis, both authors focused on data regarding work routines, reflections, and explanations for health inequities, alongside directed codes drawn from the Dahlgren and Whitehead model.

Results

Below, we describe workers' perspectives on health inequities and their reflections on applying the SDH framework. We outline how workers described their intervening in social factors beyond the individual level. Next, we describe a framework (Figure 3) to understand these results in terms of a relationship between possible frontline worker perspectives on apathy and burnout, SDH, sociological imagination, structural competency, and the right to health. Frontline workers articulate core tenets of the right to health movement, such as social and economic rights as necessary conditions for health equity, in ways that surface the complementary yet distinct aspects of structural competency and the right to health.

Figure 3 presents a novel approach to understanding the range of frontline worker responses to their own role vis-à-vis health inequities. Here, we seek to capture the dynamic, reinforcing, complementary nature of engaging with SDH via the sociological imagination, structural competency, and the right to health. We also seek to illustrate, based on frontline worker perspectives, how apathy and burnout can occur separately or together and can stall the positive momentum produced by developing sociological imagination, structural competency, and the movement for the right to health. In this approach, structural competency builds on the momentum of the sociological imag-

ination, providing a guide for collective action and direct service provision that challenges narratives of blame, bias, and the individualization of social problems. The right to health, as a framework and movement, can motivate and guide engagement with structural competency, including structural interventions that are international, politically oriented, and based in global solidarity. Analyzing the right to health in structural competency trainings will enhance trainees' ability to "observe and imagine structural interventions" (Metzl and Hansen's fourth structural competency) at a global scale. For example, codifying the right to health in more and more international legal contexts could be an example of a structural intervention with implications beyond the United States. Understanding and acting on the right to health and being surrounded by other people who are motivated by the right to health may help prevent or mitigate individual burnout. As noted by participant Sam in her interview, working at Family Center helped her see (1) social forces as fundamental to individual and overall health and (2) her own and clients' struggle as part of broad social processes rather than the result of their individual successes or failures. Given the identified connections between blame (self and client or patient), burnout, apathy, and health systems' lack of engagement with SDH, Sam provides an example of how working in an environment that *does* engage with SDH can buffer against cynicism (present in both apathy and burnout).

Importantly, these are not fixed perspectives; structural competency is an ongoing process of development that should be approached with humility.[30] The approach outlined in Figure 3 offers several important considerations from frontline workers. First, frontline health care workers apply multiple lenses to the social world at once; therefore, frontline health and social services work requires consistent reflexivity. Second, these complementary concepts may be beneficial for the well-being of health care workers and patients/clients in the clinical encounter while also fostering engagement with broader social change.

Worker perspectives on SDH

All workers endorsed the social origins of health inequities. Workers differed in which aspects of the SDH framework they found most relevant to explaining health inequity. In this section, we describe how responses fall into three levels of SDH in the Dahlgren and Whitehead model: (1) social and community networks, (2) living and working conditions, and (3) general socioeconomic, cultural, and environmental conditions (see Figure 2). Workers also highlighted that these levels often overlap with or influence one another.

Social and community networks

Five workers endorsed social and community networks as the most relevant set of SDH. For example, Marilyn—a health educator and program coordinator—noted:

> We know that [social and community networks are] the protective factor … to have parents who are supportive in social networks. There's a limit to the amount that we are able to change in the overall social world and community that clients operate within, but, to the extent that we create new communities within our clients, there's some level of an influence.

Similarly, Gabriella, a Health Team case manager, stated:

> Healthy pregnancy is a lot of things. The first thing I think of is support and not being alone in the pregnancy. It's nutrition. It is being housed. It is having the education to know how to take care of your body, access to prenatal care. I think the biggest part of having a healthy pregnancy is not being completely alone in that experience and being able to have a supportive community or at least supportive people.

These comments reflect and reinforce two fundamental dynamics observed during fieldwork. First, workers shift their practice focus and analysis between levels of SDH before landing on one. This suggests both helpful mutability in their understandings of SDH and opportunities for the agency to clarify its theory of change or approaches to the SDH framework. Second, social and community factors were more central to Family Center's pub-

lic-facing image than were other aspects of SDH endorsed by workers. Annual reports directed at funders, flyers advertising services directed at clients, and Family Center's website all emphasize the agency's health and social services as part of a mission to strengthen families and promote a positive experience of pregnancy and childbirth. In a context where overtly addressing the sociopolitical aspects of Family Center's work—such as the provision of housing and health services for marginalized people—may be alienating to politicians, funders, partners, or clients, emphasizing social and community networks may be a strategy to ensure maximum public support.

Living and working conditions

Most workers interviewed (12 of 21) endorsed living and working conditions as the most important part of the SDH framework. Four of these defined housing as the most relevant aspect of this level. This may be due to the marked lack of affordable, safe housing in the city in which Family Center operates. Consider the response of Layla, a Health Team case manager. She connects housing access to income, linking this factor to the broader socioeconomic tier of the rainbow model (Figure 1) while focusing on housing as the most salient factor in Family Center's work. She also connects housing, health, and human rights:

> I think that it's just really hard to stay healthy when you're not housed. So, I think housing is a human right, and I think that really, if we want a healthy society, we need everyone inside. And so being able to be housed is the biggest barrier. And the barriers to being housed, a lot of times, is income. Where we live it is extremely difficult to find market-rate housing that a client or that any person can afford who is not making an upper-level salary.

Michael, another health case manager, also brought up housing. He immediately connected housing (and another living and working conditions factor, water and sanitation) to unemployment:

> If you're unemployed, you're not going to have access necessarily to sanitation and water because you're not going to have a house over you, a roof over you

… so it's almost like the unemployment leads you to this [points to water and sanitation], *and the work environment leads you to this* [points to housing].

Michael's response is also an example of how workers understand the interaction of social determinants.

General socioeconomic, cultural, and environmental conditions

Three workers and the manager described the broadest level of the SDH framework—general socioeconomic, cultural, and environmental conditions—as the most relevant. This level includes a range of concepts, including economic systems and distributions of wealth and resources, norms and values, and governance structures.[31] Thus, some factors included in this level overlap with definitions of the "structural determinants of the social determinants of health." Anne, a health educator, endorsed socioeconomic conditions as the main driver of health inequity while also aligning with structural competency's "structural determinants of the social determinants of health" concept.

Well, we look at the government that we have now, and we know that we are a capitalist society, that we have a percent of the population tak[ing] 90% of the money, of what we make here, so when there's that much of a disparity with income there's always going to be people at the lower echelon, and the middle class is getting shrunk, so you get a few more richer but a lot more poorer. We could have a classless system, but we don't.

Andrea, a housing case manager, noted policy as the most important aspect of the socioeconomic tier: "I'm just thinking of policy. That's really going to make or break a community, I feel like, which is hard to explain. Just because of the people in power that have so much of a say for communities that they know nothing about." Similarly, Mayra, the supervisor and manager, described policy as a specific expression of "general socioeconomic conditions" in action:

We continue to have practices in place or limiting resources in a way that automatically excludes certain populations … I think for the Department of Housing in particular, it's very important that there be more individuals on their staff that reflect the population that they serve and or have lived experience with, having experienced homelessness or housing insecurity. That's not currently the case, and so it makes for policy that sometimes can feel nonsensical to those that are experiencing homelessness or housing insecurity because the people who are making the policies don't necessarily understand the realities of what it means to actually go through it.

Other workers described a broad social process of who is valued and who is not. For example, Sarah, a health case manager, connected wealth inequity to social norms as opposed to the presence or absence of income or access to employment:

It [the socioeconomic tier] *is so important because, well, in the US, maternal mortality is … fairly high, and similarly with infant mortality. Being able to have a healthy pregnancy and a healthy birth is something that our society doesn't throw all its resources at like some other societies, and it's so segregated by wealth.*

Here, wealth inequity is understood to be a driver of healthy pregnancy and birth. Distinct from individual-level income or employment status, which other workers described as part of living and working conditions, wealth segregation is understood to be a wider issue of socioeconomic, cultural, and environmental conditions. Notably, Sarah (who is white) does not mention racism, which is a main driver of maternal and infant mortality in the United States. This gap in Sarah's response may demonstrate that some frontline workers apply their analysis of the broader level of the SDH framework unevenly.

Innovations on the SDH framework

Three respondents proposed, unprompted, changes to the Dahlgren and Whitehead model, suggesting that frontline workers have knowledge to contribute to the development of the SDH framework or that the SDH framework can be adapted as part of workforce development. They also prefigured a key aspect of structural competency—namely, that

structures persist upstream of the top tier of the Dahlgren and Whitehead model's "socioeconomic, cultural, and environmental conditions." Jessica, a case manager, responded to the model in terms of its limitations. She found the framework useful but, as presented, too static to capture the complexity of social forces that she considered relevant to health inequity:

> I think what stands out to me about this is that there is no active blame, it's not calling out the actual structures. It's just saying like "housing, health care, water, and sanitation." Like "socioeconomic, cultural, and environmental conditions" are such a general blameless term as opposed to like oppressive structures that actively hold people down. What if those were, like, in this beautiful rainbow? I think a lot of social determinants models can remove blame and make it sound like it's like this, yeah, it's just listing things. I like how it moves inward toward the individuals, but there is no mention of racism or interpersonal violence or anything like that, capitalism, white supremacy … This is a great "101."

Marilyn, a health educator, shared that she would add a level between the Dahlgren and Whitehead living and working conditions tier and its general socioeconomic tier to describe her clients' experiences. She invoked core elements of the right to health by questioning the inevitability of health inequities and framing clients' health issues in terms of social systems of valuation or devaluation of communities who live in poverty:

> I think that a lot of the really big things that our clients are up against fit in between the outer and the second to outer category, in the intersection between how do we view poverty, how do we really think about that as a society, and how do we think about people in situations of poverty? How do we structure our society to take care of people or not? All of those things, it's kind of right in between the systems level and the community philosophy level.

Finally, Eleanora, a community health worker, suggested a need for a more dynamic visual SDH framework—one that could capture relationships between factors. The following quote suggests similar themes in the work of Jaime Breilh, Nancy Krieger, and others who have attempted to advance a model of SDH that captures the direct impact of structural forces on people's lives and survival:[32]

> I think general socioeconomic, culture, environmental conditions, I would put that much closer [to the individual]. Because I think those conditions include racism, and what kind of services are being given to the people.

Sociological imagination at Family Center

Frontline workers also discussed how the absence of engaging with the social origins of health inequities is problematic both practically and ethically. These observations display engagement with some of structural competency's core constructs. Sam, a housing case manager, stated in an interview, "Of course health is more than your genetics and your lifestyle choices, right? I mean, anyone with a lick of sense understands that, right? It's just common sense," demonstrating how, for her, possessing a sociological imagination was a practical, common-sense part of her approach to client services.

Sam went on to reflect, "I probably see things differently since I've worked here than I did before that because it does open your eyes to what people have to struggle with, which I might not have had that exact same kind of struggle, you know, within my own life." By understanding her clients' health as more than a personal struggle and her professional role in a broader social context, she demonstrated the uses of sociological imagination in a workplace where intervening upon health inequity is the goal. Her words suggest endorsement of a worldview in which health inequities are understood as reflective of and exacerbating social problems. Furthermore, she is aware of her own place in a social structure through frontline experience. This also links to structural competency's notion of structural humility.

Like Sam, other Family Center workers spoke of professional apathy and burnout as a barrier to addressing health inequity, supporting Mills's assertion that social apathy in the form of blaming those who are suffering from health inequities for their plight contributes to social problems. As noted by Eileen, a mental health clinician, "It's much

harder to make changes when you have lots and lots piled up on you. And when you've got a society that is also making you [a pregnant person] at fault."

Another frontline worker discussed how lack of sociological imagination emerged in education. Ali worked in the Health Team, focusing on outreach and service initiation for pregnant and postpartum clients. Ali was also a medical student. During our interview, in response to a question about how her medical education impacted her daily work at Family Center, she threw up her hands and stated:

> In the classroom, the material has historically been presented without any structural context on, like, why are people injecting drugs? Why might somebody experience homelessness? There just, like, isn't really any context. It's part of just like, in many cases, race-based medicine, like give African American patients this medicine, or like Asian populations are more likely to be subject to this disease. Instead of like, well, what an anti-racist care would look like, "Okay, let's look at the structural reasons for why some of these things might be true. How are people ended up in more marginalized positions, and how does that affect their health? What can we do about it? How are we changing it?"

She went on to express frustration at health and social service providers outside of Family Center who she saw as content with a "race-based medicine" approach and consciously or unconsciously relied on racial, ethnic, or class stereotypes to make decisions. She described Family Center as a counterpoint to her medical education and a broader culture in which individuals are blamed for their poor health. Ali portrayed many clinicians she encountered outside Family Center as lacking a structural understanding of how populations come to be disproportionately impacted by poor health. She also signposted structural competency's core concept of rearticulating cultural presentation in structural terms by questioning the use of "race" rather than racism to explain health inequities

Similarly, Anne, a health educator, reflected on the broader culture of health and social services present outside Family Center:

> There are core elements [of health services] that sometimes get placed on a level of unimportance, when in fact they should be the primary. So, let's say this person comes in, and they could be disregarded because, oh, they're drunk. Or they're really very poor. Let's see this person here because they look like they're dressed better, or something like that … Some people are there just to put in their eight hours, they only have four hours to go. Is that how you're measuring your day, or are you measuring your day by how you can influence health in your clients or in the patients?

Here, Anne demonstrates an understanding that social forces (classism and stigma) shape clinical interactions, shifting blame from the patient and engaging with a core skill set of structural competency. Frontline workers like Anne may be well poised to develop this understanding and engage in structural competency curricula that link poor-quality care or clinician bias with structural conditions such as profit-based health care. Anne also demonstrates alignment with the right to health by endorsing the concept that economic stratification should not determine who lives or thrives and who does not. Overall, frontline workers displayed rejection of apathy and burnout, strong sociological imagination, and, when presented with the SDH framework, endorsement of the framework as necessary knowledge in their work to intervene upon health inequity. Some frontline workers innovated on the Dahlgren and Whitehead model, suggesting that frontline workers have potential contributions to this public health knowledge framework. They also displayed components of structural competency as outlined by Metzl and Hansen. Frontline workers at Family Center engage with social and economic injustices as inextricable from health inequities, signaling their potential allyship with the right to health movement and the contribution of human rights as an animating vision to their current work. Notably, workers did not, unprompted, connect their efforts to international contexts or struggles, despite the diasporic (e.g., Latin American, Central American, Caribbean) sociodemographic profiles of many of their clients. The international nature of their clients' lives, their own work to intervene in

social determinants that have international origins and implications, and this lack of international framing of their own work suggests an opportunity to research connections (current or potential) that frontline workers may have to the right to health.

Discussion

This research reveals insights into the relationships between the sociological imagination, structural competency, SDH, and the right to health, particularly the relationships between social and economic rights violations and maternal health inequities. The perspectives of frontline health and social service workers inform SDH frameworks at a key era in SDH research and practice. Scholars and policymakers in the United States are calling for action and increased attention to structural racism following police murders and subsequent political uprisings, while the global COVID-19 pandemic has led to increased advocacy for the right to health as global practice. In our fieldwork, social and community networks, living and working conditions, and general socioeconomic, cultural, and environmental conditions emerged as most salient to the production and organization of health inequities. Frontline workers also proposed innovations to the SDH framework, highlighting the need for knowledge and practice frameworks to capture the dynamic relations of power, social hierarchy, and oppression that contribute to health inequities, in line with contemporary SDH research.

It is our emic assertion that fieldwork demonstrates that frontline workers cultivate a sociological imagination regarding health inequities because they feel that understanding clients' suffering in terms of social forces and historical context is a counterweight to apathy and burnout, which impede client services as well as staff members' and clients' well-being. Workers displayed the capacity to develop a *general* sociological imagination into an analysis of *specific* social forces such as racism and poverty that are causes of health inequities. Moreover, workers are engaged in several key elements of structural competency, including structural humility, developing extra-clinical lan-

guage, and rearticulating "cultural" presentations in structural terms. Frontline workers' thinking connects to existing frameworks of health as a basic right alongside social and economic rights as well as global social movements.

Limitations

The current study has several limitations. By excluding most managers and clients and focusing solely on frontline worker perspectives and experiences, our data are limited to certain Family Center roles. Including managers and clients could enrich the analysis of the perspectives on key issues at stake in this project: apathy, burnout, the SDH framework, sociological imagination, and the right to health. Participant observation with frontline workers at the agency itself inevitably limited our access to those workers whose duties occurred primarily outside of the agency, such as Family Center birth doulas, which may have limited our understanding of how frontline workers applied their perspectives in distinct but related contexts or settings. Future work could be comparative, transnational, or transregional. Additional research could also explore the perspectives of frontline workers in biomedical settings such as hospitals and clinics. For example, frontline workers in a hospital during the COVID-19 pandemic might have poorer working conditions (e.g., overwork, lack of personal protective equipment) and experience greater apathy and burnout, less capacity to engage in structural competency, and less alignment with the right to health. Conversely, the inequitable outcomes of the pandemic may create heightened sensitivity to SDH and more alignment with the right to health movement. Finally, choosing just one visual of SDH (i.e., the Dahlgren and Whitehead rainbow model) privileged this version of portraying SDH over others (e.g., those of the US Centers for Disease Control and Prevention or World Health Organization) and biased results toward endorsing the model presented. Here, the study methods offer a potential means of mitigating this limitation. The methods and principles of institutional ethnography, including participant observation, reflexivity, reciprocal relationships, and attunement to power dynamics

meant that the first author spent significant time in the field building relationships (e.g., as fellow commuter, fellow social service provider, fellow trainee) in addition to playing the role of interviewer. While not erasing social and institutional hierarchies between researcher and participant, such relationships can facilitate more open and transparent discussion in interviews than conventional interview methods alone.

Conclusion

These findings indicate that frontline workers are engaging with many of the key elements and questions of structural competency, such as recognizing the structures that shape clinical interactions and developing an extra-clinical language of structures. For example, Family Center workers named the physiological impacts of racism on pregnant people as socially contingent and spoke of racism itself as a social and political force. Family Center workers also connected this with the ability to empathize with clients and destigmatize the need for social services. Some workers added innovations and interpretations to the SDH framework when the Dahlgren and Whitehead model was presented to them, indicating that frontline workers have valuable insights concerning this popular public health framework. Examining and understanding their perceptions and experiences will inform education, training, and the development of an expanding SDH workforce. Where much research on SDH and structural competency has focused on clinicians, movements for the right to health acknowledge the importance of laypeople and a range of frontline workers in achieving health for all. Frontline workers may see themselves better represented in a framework that includes the right to health.

The framework offered here represents the shifts and fluctuations in frontline worker perspectives. Addressing health inequities through collective action and the right to health requires continual, shared reflection on praxis and accountability to client and patient communities.[33] Cultivating a sociological imagination is a necessary but insufficient step toward structural competency and enfranchising the right to health. By cultivating the sociological imagination present in health and social services providers, we may foster empathy with clients, prevent or mitigate burnout, inform the implementation of structural competency curricula and practice, and motivate engagement with movements for human rights, including the right to health.[34] The sociological imagination may be an important precursor for frontline workers to understand and enact structural competency and take part in the right to health as a global social movement. Existing training and curricula on the social determinants of health would be well served by approaching the sociological imagination, structural competency, and the right to health as adjacent frameworks. By demonstrating that frontline workers may be poised to put structural competency into practice and unite with the right to health movement, research can motivate future developments of this promising framework. And by understanding structural competency in relation to apathy and burnout, sociological imagination, and the SDH framework, it is possible to develop insights into the perspectives of those with the most intimate knowledge of service delivery.[35] Moreover, understanding these concepts can enrich the participation of health care workers in the collective struggle for the right to health by fostering imagination in better futures. Extending beyond health care systems, this means working toward what James Baldwin calls the "perpetual achievement of the impossible."[36] As Angela Davis reminds us, "You have to act as if it were possible to radically transform the world. And you have to do it all the time."[37]

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Disability Justice as Part of Structural Competency: Infra/structures of Deafness, Cochlear Implantation, and Re/habilitation in India

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Abstract

In 2014, the Indian state revised a key program providing aids and appliances to disabled people to also include cochlear implants for children living below the poverty line. The program is remarkable in its targeting of the poorest of the poor to provide them with expensive technology made by multinational corporations and its development of new surgery and rehabilitation infrastructures throughout India. Based on interviews and participant observation with key stakeholders, this paper argues that in focusing only on "a right to hearing" and on cochlear implants as a solution for deafness, health care practitioners ignore the complex work required to maintain cochlear implant infrastructures, as well as the advocacy work done by disability activists in India and internationally to transform existing political, economic, educational, and social structures. Since cochlear implants are the "gold standard" in intervening on hearing loss and increasing numbers of countries in the Global South have started state-funded cochlear implant programs, an exploration of India's program provides an opportunity to analyze both the importance of infrastructure and the need to combat ableism within structural competency frameworks. Disability justice is part of structural competency. Ultimately what is at stake is expanding health practitioners' ideas of what it means to maximize potential, particularly in the face of new technological interventions around disability.

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Introduction

In 2014, India's central government revised a key program providing goods and services to eligible disabled people, the Assistance to Disabled Persons for Purchase/Fitting of Aids and Appliances (ADIP) scheme. Previously, the program provided a range of devices, including wheelchairs, crutches, hearing aids, and modified scooters. In its revision, for the first time, cochlear implants were included, specifically for children under the age of six and living below the poverty line. Cochlear implants are considered among the most successful neuroprosthetics and are increasingly a gold standard in the treatment of deafness.[1] In addition to cochlear implant surgery, the central government program provides cochlear implant mapping, two years of re/habilitation therapy, and two years of warranty for the external processor. On the surface, this program appears to be an ambitious and cutting-edge program, providing listening and spoken language to deaf children through the latest technology. On the surface too, such a program and intervention maximizes the independence and agency of deaf children, as government administrators, surgeons, audiologists, and speech and language therapists stressed to me. Such stakeholders often told me, "Deaf children have a right to hear" and "Deaf children must go for cochlear implants; they are the only option for making deaf children become normal."

However, while government administrators, together with multinational cochlear implant corporations, surgeons, and allied health professionals such as audiologists and speech and language therapists, desire to develop cochlear implant infrastructure, they often do not think beyond the medical and re/habilitative process of producing a sense of hearing. That is, such stakeholders stress the importance of "a right to hearing" but not the ongoing structural and maintenance work required to maintain hearing. They focus on a one-time surgery and technological fix and ignore that cochlear implants are not a one-time solution. In addition, in focusing on cochlear implantation as "the only option for deafness," program administrators and health professionals do not consider Indian Sign Language (ISL) or other linguistic possibilities as

options, and they do not reflect on the disabling role of political, economic, educational, and social structures. Furthermore, they do not contribute to or support Indian disability activists' desires to create more accessible worlds and to combat ableism. Indeed, I learned that surgeons and allied health professionals rarely told families about ISL and that if they did, it was only mentioned as a "last resort," and often after a child had already experienced language deprivation.[2] (And note that professionals did not speak of language deprivation but rather auditory deprivation, continuing their focus on audition).

Cochlear implantation is a human rights issue in that for implantation to be successful, more than just a surgery is required; issues of differential access, varied motivations, and diverse and perhaps conflicting ideas of what it means to be a valuable and capable human being are in play. And as programs providing cochlear implants to children emerge in developing contexts and as cochlear implant companies see developing contexts as the next frontier of their work, the stakes are high.[3] Indeed, there is a paradox here: while disability is increasingly becoming normalized because of disability advocacy, there is also a simultaneous growth in so-called normalizing technologies such as cochlear implants. This paradox raises crucial questions in relation to structural competency and how health care practitioners understand the possibilities and limits of biotechnology in relation to the broader social, political, and economic context. Concerns about uneven access, the role of policies and structures, and the importance of focusing on the most marginalized people have long been at the heart of the disability justice movement.[4] In this paper, I argue that health and human rights scholars and practitioners must consider disability justice, specifically in relation to questions of economic access, infrastructure, and ableism, and that centering disability justice would strengthen a structural competency framework.

I draw from over 15 years of ethnographic research on deafness in India with ISL-speaking deaf people and with surgeons, speech and language pathologists, audiologists, families, government

administrators, and educators. Focusing specifically on cochlear implantation between 2016 and 2022, I conducted participant observation and interviews in a wide range of settings, including hospital and clinic waiting rooms and consultation rooms, schools, government offices, family homes, and international cochlear implant conferences in Indian cities such as Delhi, Bangalore, Chennai, Mumbai, and Pune. My argument is that by focusing only on "a right to hearing" and on cochlear implants as a solution for deafness, health care practitioners ignore the complex work required to maintain cochlear implant infrastructures, as well as other kinds of structural transformations needed to create more just worlds for all people.[5] They disregard the structural advocacy work done by disability activists in India and internationally to transform existing structures. India signed and ratified the United Nations Convention on the Rights of Persons with Disabilities in 2008 and 2009, and this convention goes further than any other United Nations treaty in stressing the role of social, political, and economic rights in its attempts to build a more equitable and accessible world.[6] As the convention stresses, it is important to consider social and economic rights when thinking about disability and not just abstract ideas of civil and political rights. I build on work on structural competency frameworks to analyze structure in terms of both infrastructure and the ideological structures that devalue disability and non-normative embodiment.[7] Focusing only on one sense, neglecting maintenance, and failing to see disability rights as valuable are forms of structural violence.

To be clear, I do not have a normative or prescriptive argument regarding cochlear implants and recognize that they can be transformative for people. It is exactly because they can be "life changing" that there should be enabling structures and policies surrounding their provision. If the state is going to provide them, it must also provide children with the necessary infrastructure and support to succeed, in addition to recognizing the complex role of multinational corporations and the multiple interests of health professionals. Children who ultimately stop using implants because of breakage,

obsolescence, or other reasons are often left worse off than before and are not given other options for communicating and engaging the world. My concern is ensuring that deaf children have access to language and to societies that allow them to maximize their potential, broadly defined, and not defined just as the ability to listen and speak.

What is a cochlear implant? Unlike a hearing aid, a cochlear implant bypasses many parts of the acoustic hearing system and electronically stimulates the auditory nerve to produce hearing. A cochlear implant has two main parts: a surgically implanted component (the internal part), in which the most significant element is the electrode array, and an external processor. The battery-operated processor is typically worn behind the ear and has a cable with a magnet in it that communicates with a receiver. The receiver transmits sound information to the electrode array. Each electrode stimulates a specific frequency range in the cochlea, which then stimulates auditory nerve fibers associated with that frequency. Adjusting to implant hearing takes time and work. Two to three weeks after the electrode array is inserted, an audiologist activates the external processor using proprietary software. The audiologist then adjusts the settings for each electrode and creates a range of hearing between a threshold level (the least amount of electrical stimulation possible) and a comfort level (the loudest sounds that the person can tolerate). This is called "mapping" the implant. The goal of mapping is to optimize the implanted person's access to sound by adjusting input to the specific electrodes. As the person becomes accustomed to the implant, the map needs to be adjusted, and typically the person will return to the audiologist frequently after the initial activation and mapping. Most people who receive implants can expect to have a stable map established within eight to eighteen months after activation. In addition, the external processor, much like a hearing aid, has cables, coils, magnets, microphone covers, and other breakable essential components.

Importantly, cochlear implants are manufactured by four multinational corporations: Cochlear in Australia, Med-El in Austria, Advanced Bionics

in the United States, and Neurelec in France. Each company has patented its internal components, processors, devices such as coils and magnets, and spare parts. Except for Neurelec, the companies all have headquarters in India and employ Indian audiologists and speech and language therapists. These professionals aid the state in developing newborn hearing screening and cochlear implant infrastructures around the country; they also often conduct training for surgeons and re/habilitation workers in both government and private institutions, including in locations outside metro areas. In addition, they create branded re/habilitation materials to be used by therapists and families alike and provide help with troubleshooting devices. These professionals thus support the state, surgeons, re/habilitation professionals, and implant recipients and their families; the companies often do the work of developing infrastructure.

While there are efforts to develop an "indigenous Indian implant," spearheaded by the Indian Defense Research and Development Organization, currently Indian children and their families must negotiate complex dependencies on and with multinational corporations. This is the case because families need to maintain the cochlear implant processors—the processors require cables, coils, batteries, and microphone covers, among other things—and they also must upgrade from one processor to another if the model that the family has been given becomes obsolete. Processors become obsolete at different times in different geographic locations. In India currently, and in contrast to countries in the Global North, the main processor distributed through government programs does not have noise cancellation or speech-focusing technology and, as a result, Indian children utilizing the program are implanted behind wealthier Indian children who can afford the latest technologies on the private market, as well as children in the Global North who receive implants through public and private insurance programs.[8] This decision not to provide the latest technology is particularly problematic because deaf children work through degraded signals as it is.[9] And the lack of noise cancellation or speech focus is especially egregious

in an Indian context in which schools, homes, and other everyday institutions are noisy. Strikingly, this processor was never available in the United States or Europe, and it is marketed and distributed exclusively in developing contexts, of which India is one. To be clear, multiple processors are available on the private market in India, and families with funds can purchase more expensive and newer processors. A singular focus on "a right to hearing" thus obscures political-economic hierarchies.

(Infra)structural competency and the neglected work of maintenance

According to Jonathan M. Metzl and Helena Hansen in their landmark work on structural competency, "structure implies the buildings, energy networks, water, sewage, food and waste distribution systems, highways, airline, train and road complexes, and electronic communications systems that are concomitantly local and global, and that function as central arteries in some locales and as sclerotic corollaries in others."[10] In this section, I discuss the work of building cochlear implant infrastructures and the role of national and multinational actors. I then foreground the importance of maintaining such infrastructure.

Much of the work on technology development and transfer in the realm of disability in the Global South focuses on accessibility, affordability, sustainability, and maintainability. In the international disability and development realm, there is a growing focus on the importance of assistive technology, which includes "hearing aids, wheelchairs, spectacles, prostheses and devices that support memory, among many others."[11] The Convention on the Rights of Persons with Disabilities advocates for state parties to ensure the provision of assistive technology for everyday life (article 20) and in rehabilitation (article 26). It also stresses that assistive technology can be a leveler in empowering people with disabilities and that nation-states should share technical and scientific research related to the development of such technology (article 32).[12] However, as John Borg, Stig Larsson, and Per-Olaf Östergren point out, despite this emphasis on the

importance of assistive technology, "except for personal mobility, the [Convention on the Rights of Persons with Disabilities] seems not to give persons with disabilities the right—or legal support—to approach their government to demand necessary assistive technologies at affordable cost, which for many may be at no or very little cost."[13] In research on wheelchairs and other assistive aids in the Global South, scholars and practitioners have pointed to the importance of technology that is accessible and maintainable, and available to be repaired using locally sourced materials.[14] In India, the growing field of assistive technology focuses primarily on individualized technological solutions. Incubators and accelerators funded by the Indian government and corporations encourage the development of sustainable assistive technology, an individualized infrastructure.

The World Health Organization, in collaboration with national government agencies and nongovernmental organizations, has produced handbooks such as *Guidelines on the Provision of Manual Wheelchairs in Less Resourced Settings* (2008) and *Preferred Profile for Hearing-Aid Technology Suitable for Low- and Middle-Income Countries* (2019), which explicitly discuss sustainable design and maintenance. The World Health Organization, however, has not released any such guidelines for cochlear implants, although in its 2021 *World Report on Hearing*, it (vaguely) mentions the importance of sustainable cochlear implant programs. While a hearing aid is considered assistive technology, a cochlear implant processor is not. Yet the same issues of affordability, access, and maintainability exist for the external processor as for a hearing aid; batteries, coils, cables, microphone covers, and magnets, among other things, must all be maintained and often replaced.

India's ADIP scheme is also concerned with affordability and sustainability, and it has focused on manufacturing aids and appliances in India. The scheme began in 1981 with a stated goal to

> assist the needy disabled persons in procuring durable, sophisticated and scientifically manufactured, modern, standard aids and appliances to promote physical, social, psychological

> rehabilitation of persons with disabilities by reducing the effects of disabilities and at the same time enhance their economic potential. Assistive devices are given to [persons with disabilities] with an aim to improve their independent functioning, and to arrest the extent of disability and occurrence of secondary disability.[15]

The ADIP scheme's goal is thus to maximize individual functioning through the provision of individual devices and technologies.

In 2014, in response to negative perceptions and in a desire to technologically scale up under the ruling Bharatiya Janata Party's "Make in India" campaign, the ADIP scheme began including "modern" and "technologically complicated" devices such as electric tricycles, smart canes, and digital hearing aids. Also in 2014, following the establishment of state government cochlear implant programs in Kerala, Andhra Pradesh, and Tamil Nadu and in the Indian Armed Forces' health services, cochlear implants were added to the ADIP portfolio for prelingual deaf children five years of age and under (exceptions are made for children up to six years of age) and postlingual children under the age of twelve who lost their hearing after the age of four or five. To be eligible, children cannot have additional disabilities.

To receive a cochlear implant through the scheme, the child's family must have monthly income below Rs 15,000 (US$198). Partial inclusion in the scheme is possible for families with income below Rs 30,000 (US$396) a month. The government purchases cochlear implants from one of four major manufacturers through a competitive bidding process through which the contract is awarded to the lowest bidder that meets specification requirements. The cochlear implant is by far the most expensive device distributed through the ADIP scheme. The total package costs Rs 6 lakhs (US$7,934) and covers implantation, the external processor (which has a two-year warranty), batteries and replacement cables and coils, and two years of re/habilitation at an institute or provider enrolled in the program. By way of comparison, the second most expensive device under the scheme is an electric scooter that costs Rs 36,000 (US$476). According to ADIP

guidelines, hearing aids for school-going children can cost up to Rs 12,000 (US$157), while hearing aids for everyone else are covered up to Rs 10,000 (US$132), a significantly smaller financial investment than that for a cochlear implant. The cochlear implant program is an ambitious flagship program that is often featured in the popular media in heartwarming stories about children who can now hear and speak thanks to the generosity of the state and the skilled work of surgeons.[16]

To learn how cochlear implants came to be included in the ADIP scheme, I interviewed a man I call Alok Sharma, a former joint secretary in the Ministry of Social Justice and Empowerment. Sharma is an Indian Administrative Service officer who is much respected by both the mainstream disability community and re/habilitation professionals for his ability to get things done. Sharma efficiently and energetically told me that the ADIP scheme was revised when the ministry realized that new technology was available and that the current level of funding per beneficiary was very low. The ministry sought out stakeholder participation, including input from the All India Institutes of Medical Sciences, the Ali Yavar Jung National Institute of Speech and Hearing Disorders, cochlear implant surgeons, cochlear implant distributors, and the Ministry of Health (there was no participation by signing deaf individuals or groups). Sharma continued: "And based on this stakeholder participation, we found out that if we do large-scale cochlear implants within the country, then the process of implementation of the cochlear implants will become popular, the cost of cochlear implants will come down—because it would get government supported." He also said that because of "a transparent process using web-based platforms and application portals," "large-scale" cochlear implantation is now happening in India. He summarized his work as follows:

We did three things. One, we brought down the prices of cochlear implants. We brought into India a culture of cochlear implants. We brought the culture of training the children, after the cochlear implants, with their parents. As well, we brought a culture

of getting the doctors to do the surgery also. There are a large number of government hospitals which undertook the surgery. We empaneled the hospitals, we empaneled the doctors. All that also happened. So ultimately, it was an all-round process.

As Sharma noted, private and public hospitals all over India have been empaneled (enrolled) in the program to perform cochlear implant surgery. Surgeons are mentored by more experienced surgeons who are sponsored by cochlear implant companies, the hospitals, or the state. Audiologists and speech and language therapists have also been empaneled.

Every application for an implant through the ADIP scheme is uploaded onto a central government site along with the required paperwork, such as audiograms, CT scan results, medical reports, disability certification, Aadhaar number, proof of income, and birth certificate. After someone is approved for a cochlear implant, he or she is placed on a waiting list, which—in the interest of transparency—is available for public viewing on the ADIP web portal. As implants are delivered by the contracted companies, the Ali Yavar Jung National Institute of Speech and Hearing Disorders slowly and incrementally sends them out to the empaneled surgeons and facilities. Families then receive notification that they are to report to a hospital for surgery; the surgery typically requires an overnight stay.

Approximately three weeks after surgery, families report to an audiology clinic for activation. Cochlear implant activation videos are ubiquitous on YouTube and other social media. In a typical video, the camera focuses on a small child as the child's implant is activated in a clinic. The child ostensibly hears or senses something, celebratory tears are shed, and the child is sent back out into the world—the child, the family, the implant, and the new sense of hearing. However, this is not all that happens when a cochlear implant is activated, or "switched on." At the time of activation, the family is given a large kit in a cardboard box, a duffel bag or backpack, or a hard-plastic box, depending on the manufacturer. The kit contains individually wrapped spare magnets, cables, batteries, battery chargers, microphone covers, small tools for clean-

ing the processor, and a thick instruction manual, among other things.

And this is where infrastructure breaks down: most of the Indian families I met received no information about implant components and the need for their care and maintenance practices before activation. While I observed audiologists discussing the external processor with prospective families during orientation sessions, I never saw a discussion of cables, coils, or even batteries. Families typically did not see these things until activation day. Some audiologists informed me that their practice was to activate the implant and then give the kit to the family. They would then send the family, lugging the kit, to lunch or tea "to process everything" and tell them to return to the clinic afterward. At that point, the audiologists would explain the care and maintenance processes and go through the objects in the kit with the family. Although these things are not included in the cochlear implant activation videos that circulate online, for the family, receiving the kit and learning about the different devices, cables, batteries, and spare parts and their maintenance is a significant part of activation.

On the importance of maintenance and repair, Stephen Graham and Nigel Thrift write, "It becomes increasingly difficult to define what the 'thing' is that is being maintained and repaired. Is it the thing itself, or the negotiated order that surrounds it, or some 'larger' entity?"[17] As Graham and Thrift stress, concerns about maintenance are not just concerns about particular devices, here cochlear implants; rather, they index larger issues within a structuring order that are political as much as they are personal.[18] Indeed, while the state argues that cochlear implant maintenance is a personal expense and responsibility, I see this individualizing of maintenance work as a political move that absolves the state of responsibility.

Arguing that scholars and laypersons alike are overly attentive to innovation and ignore maintenance, Andrew Russell and Lee Vinsel define maintenance as "all of the *work* that goes into preserving technical and physical orders."[19] With regard to maintenance and repair, scholars have analyzed the emergence of informal maintenance

and repair workers who creatively tinker with and fix things—particularly mobile phones and televisions and stereos using recycled and repurposed parts.[20] In contrast to this body of literature on the important work of maintenance and repair, cochlear implants represent a hard limit to this discourse. While families and individuals can maintain external processors (albeit only for so long) through daily cleaning routines, they cannot repair these devices. "Spare parts" must come from cochlear implant corporations or licensed suppliers, and they are prohibitively expensive, with a cable or battery easily costing a half a month's salary or more for a low-wage worker.

Some state programs, notably those in Kerala and Tamil Nadu, provide lifelong maintenance support in their schemes, including free replacement parts, but the processes that families must go through to get replacements and repairs involve many bureaucratic steps and are often inconsistent. Government officials and other stakeholders know that people cannot afford maintenance or repairs, but it is easier to critique parents than it is to blame political-economic structures.[21] Indeed, a government audiologist once told me, "This scheme is exactly for people who cannot afford to maintain implants," while many surgeons told me vaguely "people will find a way to maintain the devices" after implantation. After implantation and a two-year period, families are on their own. Stories abound of children who have become "nonusers," or gone "off-ear," with the blame for their noncompliance placed squarely on the families for being lazy or careless, or for not saving up the money needed to maintain their children's implants. Indeed, during my research, surgeons and allied health professionals often told me that if families did not pay for anything, they would not value the devices, which was contradicted by what I saw in the field: parents who admonished their children not to play during school recess in order to avoid their devices breaking, parents who would not permit their children to go out in the rain for fear of water ruining devices, and parents who begged their children's teachers and schools to keep an eye on their child's processors. Such parents know that they will be blamed

for device breakage or, more importantly, that they will struggle to afford repairs.

This analysis of the ADIP scheme points to the importance of both maintaining infrastructure and thinking about infrastructure across different scales. While the state has focused on developing a country-level cochlear implant infrastructure, it has neglected to think about the ways that this infrastructure is enacted in individual bodies and relationships and the complex work that families must do to maintain this infrastructure. "A right to hearing" might be replaced or at least augmented by a right to maintenance and repair or a right to a functioning device that does not cause families to need to make impossible decisions about whether to buy food or implant batteries.[22] Ultimately, families must engage with cochlear implant manufacturers themselves, which may have different motives and goals than the state. It is thus crucial that concerns about maintenance and repair—and who is responsible for such acts—become part of discussions about structural competency.

Ableism and structural competency

A singular focus on the right to hear also reflects assumptions about what it means to be a valuable human being. Metzl and Hansen note in their work on structural competency that "structure connotes assumptions embedded in language and attitude that serve as rhetorical social conduits for some groups of persons, and as barriers to others."[23] In this section, I focus on the need for an analysis of ableism, or beliefs and practices that devalue and discriminate against disabled people, as an essential part of structural competency. I then argue for the importance of political, economic, educational, and social work to create more enabling infrastructures; such work and infrastructures can serve to combat ableism.

Deaf communities around the world, including in India, have had strongly negative reactions to cochlear implants, and they have been called unethical and unnecessary. For example, Paddy Ladd writes that cochlear implantation is an example of "neocolonialism"; motivated by economic profit, it imposes scientific technology on and in deaf people.[24] Similarly, Harlan Lane argues that cochlear implants are a means of controlling, medicalizing, and disabling deaf people and that their use will lead to the "eliminat[ion] of Deaf culture, language, and people.[25] Such strong positions have increasingly become nuanced, with more sign-language-speaking deaf people in the Global North choosing to get implants as teenagers and adults while also remaining involved in deaf communities. In contrast, very few of the Indian surgeons, audiologists, and speech and language therapists whom I interviewed had any awareness of India's deaf communities, dense social networks, or cultural and sporting clubs.

Surgeons, audiologists, and speech and language therapists often stressed to me that they thought it was "very difficult" to be a deaf signing person in India, that few people knew ISL, and that there were few schools and employment sites available for signers. I also attended cochlear implant conferences in India where surgeons and re/habilitation professionals (dismissively) spoke of American Sign Language or just an unmarked "sign language," thus revealing that they were not aware of the existence of ISL, let alone state efforts to institutionalize ISL with and through the Indian Sign Language Research and Training Center. In observations of speech and language therapy sessions, I noted that therapists often spoke of "total communication" or "gesture" instead of ISL; they also never mentioned the possibility of ISL-based early intervention or education. In one remarkable exception, the chief orator at an Indian cochlear implant conference in 2019 was an experienced audiologist and speech and language pathologist who used her platform to stress the importance of ISL and to point out that both Indian disability laws and the Convention on the Rights of Persons with Disabilities mention sign language. She asked those present to stop ignoring ISL's existence and to educate themselves about it. The audience listened politely, and then subsequent presentations returned to the topics of surgical techniques and the importance of bilateral implantation.

Performing cochlear implant surgeries and

working with cochlear implant recipients are considered prestigious and lucrative professions.[26] Cochlear implant surgeons have revered status, as they are seen as the people who make children hear, and their expertise is unquestioned.[27] However, and unfortunately, they often disparage other paths for deaf children and do not see the importance of educating themselves or families about the effects of language deprivation and the need to nurture and support multiple re/habilitative paths involving senses other than audition and modalities other than verbally speaking. For example, I interviewed a Delhi-based surgeon about someone whom he had implanted when the child was five. The child was 11 at the time of our interview and was not listening or speaking; his implant had also broken, and the family did not have funds to replace it. I asked the surgeon what he thought should be done and I wondered if the child should be referred to a sign language-based school. He told me that he did not support this idea because the child should learn to listen and speak. He was unaware of the family's financial struggles and the heavy burden they were experiencing. Indeed, in this case, the family's struggles affected not only the child's hearing but the mother's health. Since they had migrated from a rural area to Delhi and were living in a dense neighborhood, the mother had contracted tuberculosis and had to then avail herself of government tuberculosis programs.

Another example of a surgeon who refused to consider options other than speech: I met a surgeon who performed surgery on older children who did not become listeners or spoken language users; other surgeons, audiologists, and speech and language therapists had criticized his work. To restore his reputation, Praswant Bal created an app for mobile devices that allows deaf children to learn sounds (not language) by seeing immediate feedback on their production. Children using the app look at the screen and practice pronouncing "ma," "ta," "pa," and other sounds, and the app tells them if and when they are vocalizing these sounds properly. The app's brochure claims that in trials, "completely deaf and mute persons" have learned to utter eight sounds in a matter of weeks. Bal's proj-

ect has been funded by the central government: it fulfills the state's desire for innovative and technological projects that utilize existing infrastructure and are "make in India." A state government was excited about the project and permitted a pilot in deaf schools in the state, in which the children used instruction time to practice uttering sounds. This brings up questions about privileging the production of sounds over learning language and subject content—perhaps in ISL. The surgeon was uninterested in ISL, insisting that it could not be used to communicate effectively in the world. He was also unconcerned about a deaf school using instructional time to teach sounds instead of language or academic content. He instead focused on feedback from parents who were ecstatic that their deaf children were uttering the sounds "Ma" and "Pa." This surgeon's endeavor articulates with points made in the previous section—the state's desire to create technical infrastructures and the valuing of such infrastructures above all else—and the ways that these desires often result in obfuscating other possibilities such as learning ISL and becoming a signer.

Health care practitioners must analyze their biases in relation to deafness and disability because such biases impact the kinds of choices families might have, as well as the current and future availability of enabling social and economic infrastructures. Disabled people consistently report their quality of life as being higher than what is expected or assumed by non-disabled people.[28] Disability studies scholars have often stressed the importance of a social model of disability in which social, political, and economic barriers to daily life and participation are the focus of remediation; cure comes from social fixes.[29] More recently, scholars have called for an explicitly political-relational model of disability that analyzes how disability is a political category created in relation to norms and structures.[30] What would happen, then, if health care practitioners saw and presented to parents ISL as a viable and valuable option? Why is cochlear implantation considered the only option and path available? Indeed, health professionals often possess a narrow definition of what it means

to be "normal," and this points to the necessity of political, economic, and social work to create more enabling infrastructures.[31]

Disability justice as a key component of structural competency

Health and human rights scholars have stressed the need to focus on more than just civil and political rights; they argue for the importance of social and economic rights and emphasize that health care practitioners have a role to play, particularly in how they understand the role of the state and the impact of political-economic structures in creating health care inaccessibility.[32] Recently, disability justice scholars and activists have called for recognition of the ways that disability is an intersectional issue and of the relationships between disability, race, class, geographic location, gender, and capital, among other things. These scholars and activists have pointed to the importance of nuancing disability rights frameworks to address the workings of power and inequality.[33] Additionally and importantly, I argue that they provide a much-needed expansion of how scholars focusing on health and human rights have thought about access, infrastructure, and ability.

In *Ten Principles for Disability Justice*, Patty Berne and the Sins Invalid Collective call for an approach to disability that is anti-capitalist, sustainable, and rooted in the experiences and expertise of those most impacted by oppressive social and economic systems.[34] While Berne and Sins Invalid have proposed principles that emerge from their work in North America, I see deep resonances and the need for a structural competency approach to also engage with questions of disability justice, especially in relation to infrastructure and structure more broadly. Their principles point to the importance of critiquing intellectual property regimes that make cochlear implant maintenance and repair so costly, as well as the absence of deaf people involved in leadership and advisory positions within cochlear implant and re/habilitation infrastructures. The movement and the principles also emphasize the importance of focusing on intersectionality and multiple and often competing needs.

During the early days of the COVID-19 pandemic, for example, the father of a child who received a cochlear implant through the Indian central government program wondered why the government had not given them food or money instead of a costly device that the family cannot afford to maintain. The same father said that he and his family were just trying to stay alive. Such statements stress the importance of considering "the right to hearing" in relation to other rights.

In the case of cochlear implantation, health care practitioners must consider the complex dependencies that are created as the state implants young children and as families become dependent on multinational corporations for maintaining and repairing their implant processors. While health care practitioners might work with a family for a finite time, that family's relationship with cochlear implant manufacturers is for a lifetime. The relationship does not end after surgery or at the time that a child might attain so-called age-appropriate listening and speaking skills. This dependence is all the more fraught because families are often not aware of other options besides implantation. Beyond this physical infrastructure, ableism is a structure of thought that serves to limit possibilities for treatment, care, and ultimately all aspects of everyday life. Regardless of hearing status, all children have the right to maximize their potential. Health practitioners have a role in expanding how we might measure potential more broadly; potential does not just start and stop at hearing.

Acknowledgments

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Growing Up Can Be Hard to Do: Reimagining Structurally Supportive Pediatric-to-Adult Transitions of Care from a Rights-Based Perspective

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Abstract

Extended life expectancies and shifting dynamics in chronic disease have changed the landscape of public health interventions worldwide, with an increasing emphasis on chronic care. As a result, transition from pediatric to adult care for medically complex adolescents and young adults is a growing area of intervention. Transition medicine is a nascent field whose current emphasis is on middle- and high-income countries, and thus far its methods and discourse have reflected those origins. Through several case-based examples, this paper aims to highlight the possibilities of an analytic approach grounded in structural competency for transforming transition medicine through a human rights-based framework, with an emphasis on imagining a more global framework for transition medicine. Our cases highlight the disparities between patients navigating pediatric to adult-based care, illuminating social stigma, stratification between public and private insurances, engagement in risk-taking behaviors, family conflict, and challenges with transition readiness. To reimagine transition medicine so that it is based on human rights, we must prioritize structural solutions that embrace multisectoral integration and holistic mental health support rather than oppress and marginalize these critical systemic adaptations. We aim to reconfigure this scaffolding to center structures that integrate holistic well-being and imagine alternate realities to healing. Our work contributes to the literature bringing structural competency to new spaces of clinical practice, contextualizing new frontiers for the exploration of chronic diseases across diverse clinical contexts worldwide.

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Introduction

As extended life expectancies and shifting dynamics in chronic disease change the landscape of public health interventions worldwide, chronicity has become a growing area of study. Gains in life expectancy pose new challenges for ensuring the health of populations in diverse socioeconomic, political, and cultural contexts. Of particular interest to this paper, gains associated with "Western" biomedicine have enabled many with pediatric-onset diseases to live into adulthood. In the United States, Canada, Australia, and Western Europe, ensuring the safe transition from pediatric care to adult care has grown into a burgeoning clinical and research field organized under the framework of transition medicine.

Transition medicine is a nascent field that has traditionally been salient in high-income countries, with its methods and frameworks reflecting these origins. To the best of our knowledge, frameworks and structures around pediatric-to-adult transition have been shaped by the resources—both cultural and material—available in places like the United States, Canada, and the United Kingdom.[1] Though unique challenges present themselves depending on the overarching health system (e.g., US individualized health insurance versus the National Health Service in the UK), many common themes present across these geographically and culturally diverse situations.[2] Transition medicine is a diverse and vibrant field that has maintained close attention to the lived experiences of transitioning young adults and adolescents and centers its work and study around health care transition (HCT) for children and youth with special health care needs.[3] HCT is the formal model for standard of care utilized by those who practice transition medicine. This emphasis on HCT has generated frameworks, such as SMART, which allow for understanding transitioning youth (from pediatric to adult-based care) in context and for predicting and maximizing transition readiness.[4]

Adolescence is a critical developmental stage with important milestones, including increased desire for independence, self-discovery around sexuality, and emotional regulatory changes, par-ticularly sadness and depression.[5] Without secure support through this transition, those already marginalized are at increased risk for further morbidity. Important to this work is the recognition that HCT could benefit from attention to structural oppression that unequally affects youth with chronic diseases and demonstrates the limits of existing systems in addressing these patients' needs. Access to culturally responsive, situationally appropriate care is a priority for all youth but is particularly vital for those with chronic conditions or living with disability. While social-ecological frameworks have been integral in framing youth at the center of competing forces that affect readiness for and success in transition to adult care, greater attention to structural inequality would benefit the field as we imagine an expansion of its principles to diverse global contexts. An emphasis on structural competency in the design and evaluation of transition programs, as well as the framing of these resources as a right to be fought for, is key.[6] As advances in modern biomedicine have allowed for extended life expectancies, there is a need for a human rights-based approach to ensure the dignity and longevity of adolescents and young adults with chronic illness. It is, as we argue, our obligation to actively dismantle structures upholding and perpetuating inequity in this already vulnerable population.

The evolution of a rights-based model to transition

We ground our argument for HCT in an attentiveness to the right not only to health, but to the civic, political, and economic rights that enable youth to flourish in their communities.[7] This paper, an outgrowth of interdisciplinary and transnational collaboration in Ghana and the United States, is rooted in the conviction that transition support is an important site of intervention for ensuring the rights of adolescents and young adults living with chronic disease worldwide.[8]

While this paper is not the outcome of a formal qualitative research study, it is the product of over a decade of collaborative research between several authors of this paper. Thus, while this piece

is not an ethnography, it is deeply ethnographic insofar as it draws on the ethos of deep participatory exploration, collaboration, and communication.[9] This collaboration is rooted in a long-standing working relationship between two of the authors (LR and CKH) through a variety of projects regarding transition-age youth. Their conversations, built from shared experience working on these issues in Ghana, formed the impetus to engage this topic. Another Boston-based collaborator, LL, has worked with LR in a transition clinic in Boston. Many of the challenges identified in transition medicine in the United States emerged from this working relationship. Recently, Philadelphia-based author MM began engaging with this team regarding challenges in transition medicine with a global lens rooted in structural competency, cultural humility, and anthropological thought and methods. Drawing on both her anthropological expertise and the other collaborators' years of experience, our team started with a series of open-ended, though often case-based, discussions taking place over the course of several months, engaging in a constant comparative method akin to that which undergirds grounded theory.[10]

Early conversations took the shape of brainstorming about the challenges we face with transition-age youth in our clinical disciplines and locations.[11] Subsequently, we began organizing these freeform conversations into thematic buckets, refined until we reached collective agreement.[12] Our goal was twofold: more practically, we sought to problem-solve issues we had seen in all three locations; more globally, we sought to imagine a future for global transition medicine. Ultimately, the themes elucidated in this paper emerged from these conversations among the authors which highlighted challenges with HCT in our respective clinical practices. Through these conversations and experiences, we noted patterns that could be addressed most holistically by applying a rights-based approach. To further support the exploration of this framework, we engaged the transition medicine literature to understand if this had ever been done before; literature referenced was chosen for its salience to practitioners in transition medicine,

with additional PubMed searches performed for resources regarding the HCT approach and its relationship to inequality and marginalization. Thus, the selection of our rights-based framework emerged from these collaborative conversations, our thematic exploration, and consensus after review of the literature, read against our collective clinical experiences. What emerged is a consensus view of these authors regarding challenges and opportunities embedded in existing transition frameworks.

Frameworks in transition medicine: Identifying existing challenges

As patients with pediatric-onset disease live increasingly into adulthood, transition medicine has become a growing field in many resource-rich settings. Optimal transition is not simply the transfer of providers but rather an integrated, systematic response to support the transfer of care from a pediatric to an adult medical home.[13] Systemic and structural support is important (e.g., transferring medical records, finding new sub-specialists), particularly at this time of developmental transition. We acknowledge that adolescence has salient representations across cultures, where it may be framed as a unique developmental period of major life transition, though noting that this period may be framed differently in different contexts.[14] While the social salience of adolescence varies, institutional structures related to pediatric versus adult care mean that this time is a significant period of transition. Adolescents and young adults with chronic medical conditions who may have grown up with their pediatric providers like family members must move on.

Moreover, in many contexts, this developmental period is marked by increased personal independence, often guided by adult role models. Medication and therapeutic adherence is most vulnerable during this transition given that adolescents and young adults can lose sight of self-management as their caregivers and providers give increasingly more autonomy.[15] This can be particularly at risk when these relationships are also in flux during this

period.[16] Many innovators have sought to integrate skills-based learning to help these patients grow into their roles to self-navigate, self-advocate, and self-manage their chronic disease.[17] This is particularly important for those with multiply marginalized identities who must also navigate bias.

Though pediatric-to-adult transition medicine is still new, the commonly accepted methodology usually includes certain standard elements: (1) transition policy; (2) patient registries (tracking and monitoring); (3) readiness assessments; (4) planning; (5) transfer of care; and (6) transition completion with post-transition feedback.[18] Though these elements can serve as building blocks and integrate into existing health care infrastructure, they often center dominant identities. One example of these elements is the concept of transition registries. Rarely, if ever, do transition patient registries intentionally collect data to measure patient-facing equity indicators (e.g., self-identified gender, ethnoracial categories, or socioeconomic status), structural influences, or identities that may reflect how that patient interacts with the system and how the system then interacts or interferes with their ability to feel safe and cared for. Data typically collected on registries include name, date of birth, documentation of current and future providers, and readiness assessments. Gottransition. org, which has set the "gold standard" for these templates, has no mention of collecting ethnoracial data, gender identity, or socioeconomic or insurance status, undermining the critical importance that this type of data has on the patient's and family's ability to have a safe and successful transfer of care. As noted by Maria Diaz-Gonzalez de Ferris et al., without intentionally collecting data on types of insurance, primary language, or other ecological factors impacting care, certain communities are disproportionately marginalized.[19]

Transition-readiness assessments also often value a notion of self-advocacy within certain culturally bound developmental milestones that are framed as universal, failing to account for both cultural variation in the valorization of these traits and structural barriers to enacting these ideals where they are valued. Following Jonathan Metzl and Helena Hansen, we place greater emphasis on structural barriers and inequalities and are hesitant to fall back on cultural frameworks for understanding differences in transition readiness.[20] One question included in the Transition Readiness Assessment Questionnaire, a commonly used and validated readiness assessment, asks "Do you get financial help with school or work?" as an indicator of transition readiness. We are advocates for detailed social histories, which can provide valuable information for provider-driven resources.[21] Therefore, we recognize the importance and careful crafting of the Transition Readiness Assessment Questionnaire as an instrument, but can also imagine a scenario where this is being asked by a white provider in the United States to a young person of color who recently lost financial aid due to struggles with substance misuse. Or we might consider this being asked of a young adult who was not able to submit applications for assistance because they were recently incarcerated. We propose that these questions are important questions to answer not as a marker of readiness but as a point from which to strategize around structural barriers needed to overcome to provide rights-based and equitable transitions of care. These conversations could be integral to the process of "warm handoffs," a recommended component of transition care in which providers discuss patients undergoing HCT.

The above examples reflect just a few existing challenges in transition medicine. Our observations of patterns in this work underscore the variations in rights and access to services across the geographic spaces in which we practice. In the United States, where many of our collaborators are based, steep hierarchies exist across racialized, classed, and gendered lines, making access to care and safe transition deeply variable.[22] In Ghana, based on our experience, similar but overlapping challenges exist, framed in colonial perceptions of care equity. Colonial notions promote the ideal of "Western" care as the gold standard. Without understanding the local context, these notions further create inequities in Ghana. In our work, we have observed the following patterns that have shaped our impetus to evolve and restructure how we practice transition

medicine.

With a failure of empowerment, accountability, and participatory approaches, transition often flattens differences between patients and their desires for seeking care. People living at the intersections of multiple marginalized identities tend to suffer disproportionately, and transition programs, where they exist, intentionally allow for provider discretion in handling care to promote a patient-tailored response.[23] Though this can be extremely beneficial to patients' unique needs, it leaves room for both implicit and explicit bias in the handling of the transfer of care. Additionally, diversity in clinical and healing perspectives is not often allowed for. Those seeking care with both "traditional" and biomedical practitioners of healing are often caught in the middle. The minimal integration of "traditional" and "Western" medicine often makes patients choose between the two, specifically in lower- and middle-income countries like Ghana. By doing this both within HCT and within the greater context of medical pluralistic hierarchies, we fail to recognize that our patients and their families have deep-seated beliefs in traditional practices.[24]

Patient "desirability" often shapes transition practices, and without legality and accountability embedded in health care structures, further marginalization is a result. As previous scholarship has demonstrated, the perception of the "difficult" patient is not equally applied to all populations.[25] This is no less true in transition medicine. In our collective experience, those with histories of substance misuse, or behavioral concerns that manifest themselves in anger or violence, are more often escorted to adult care.[26] Meanwhile, those who are well established with mental support are often kept in pediatric-based care. In the United States, patients from non-white backgrounds are disproportionately described as "difficult" or "angry," as opposed to a recognition that, for example, "this family advocates for themselves well." This further illustrates that not all advocacy is perceived the same, and sometimes this perpetuates inequity when it is transformed into a tailored transition experience.

The lack of nondiscrimination and equality structures promotes the recognition of those with chronic issues of childhood as a "special group"—a recognition that does not get applied equally. In the United States, where a robust system of tertiary and quaternary care exists, providers often face challenges with families and patients who are long convinced of their unique characteristics and who feel entitled to particular rights. In our transition clinic in Boston—where, in order to be referred to the clinic, patients must have at least five comorbid conditions or significant psychosocial vulnerability—we often find that those with privileged identities introduce as "the sickest patient or most unique patient" we have ever met. Typically, the patients who self-identify as especially vulnerable are often not those identified by providers as the most in need. The patients with the most vulnerability (both relative to structural determinants and chronic disease acuity) are usually more reticent to advocate for themselves or to self-identify in a way that suggests that they feel that the system is not supporting them.

These challenges, in addition to differences in ability to pay for care, access services, and navigate systems, permeate our experiences in transition medicine.

Toward a global transition medicine: Rights-based frameworks for adolescent and young adult care

Transforming transition medicine within a global lens requires an attunement to the unequal landscapes in which this field is practiced. Moreover, thinking about these practices and policies on a global stage, it is imperative that we also mention the role of colonialism in centering Eurocentric understandings of pediatric-to-adult transition medicine globally. We thus draw on work at the intersection of structural competency and human rights to ground our case analyses. Structural competency and related frameworks, with their interdisciplinary emphasis on health across sociopolitical contexts, offer the ability to ground our practice of transition medicine in the lived experiences of adolescents and young adults in diverse

sociopolitical contexts, understanding that the needs of adolescents and young adults living with chronic disease vary depending on local communities, their resources, and their sites of struggle.[27] In this sense, successful HCT will not look the same in the United States as it does in Ghana.

One model, the SMART model of transition—which elaborates 11 domains of transition medicine, from relationships to beliefs to skills and self-efficacy—focuses primarily on the individual or family unit undergoing HCT. Notably, the model includes one category, "pre-existing factors," which are described as less amenable to change.[28] These include sociodemographic and cultural factors—"age, ethnic/racial identity, socio-economic status (SES), culture of family and community," and gender and sexuality—that may impact HCT.[29] While these factors are bracketed in this model, we believe that they are essential to the understanding of how to build equitable HCT structures worldwide. We thus instead conceptualize the adolescents and young adults as existing at the center of multiple overlapping domains (see Figure 1)—their kin networks and local communities, the institutions (medical and otherwise) that they navigate in transition, the health care and educational infrastructure of their society, the cultural norms and ideologies that shape their identity, the way they navigate the world, and the global flows of information and power that shape the health care they have access to. As a result, we propose a structurally informed expansion of the socio-ecological SMART model informed by our transnational collaborations in HCT. Our fundamental argument is that a safe, structurally aware, and interpersonally supportive transition to adult services is a key component of the right to health for all people, particularly medically complex and vulnerable youth.

Pediatric-to-adult transition lends itself well to a rights-based approach. This has been imagined through the PANEL framework, which utilizes five main principles: participation, accountability, nondiscrimination, empowerment, and legality.[30] Participation refers to equity in participation for all stakeholders in decision-making. Accountability within a rights-based framework ascertains that "duty bearers" are held accountable to "rights holders." It would be fair in this context to define rights holders as adolescents and young adults with pediatric-onset disease and duty bearers as the health system at large. Under the principle of nondiscrimination and equality, all rights holders are entitled to equal access to care. There should be no discrimination of care based on one's ability to pay for transportation or communicate in common or colonial languages, for example. In terms of empowerment, many such adolescents and young adults are often part of many traditionally non-dominant communities, with common identities of neurodiversity or disability. It is critical that these communities and individuals have systems-level empowerment so they can adequately navigate the system and self-advocate for their care in equity with other individuals and communities from dominant societal groups. Finally, legality refers to the need for congruence in legal rights.

From personal to structural: Cases in transition medicine

The United States: Navigating generational trauma and systemic bias

Let us consider a 21-year-old second-generation Haitian American woman, Rose. Rose was born in Haiti but grew up in Boston and recently graduated from a four-year university with a bachelor's in science. She is currently working at a tech start-up where she does not have employee-based health insurance. She carries a diagnosis of bipolar disorder and a more recent diagnosis of non-insulin-dependent diabetes. Given her age, Rose is no longer able to see her pediatrician for care, so she has gone without care for several years and is unsure where to go next in light of her insurance gap. She is working on applying for public insurance to find a new adult provider, a challenge that forces her to encounter the lack of availability and accessibility of services for those with public insurance, especially at transition age.

Rose's mother has been somewhat skeptical of her seeking care, based on several traumatic events they both experienced while hospitalized upon first

moving to the United States. Her mother often cries while telling stories of being stuck with needles and given medication while in the hospital without the use of an interpreter. The lack of participation in her own care has left her with traumatic memories. She shares that she felt terrified not knowing what she was given or why. After being given the medications in the hospital, she often woke up more tired, confused, and unsure of how to ask for help. She was never even told exactly what was wrong with her at the time or how to take care of herself after being discharged. Partially driven by these experiences, when our patient talks with her mom about her own feelings of depression, her mother often first suggests traditional Haitian models of care.

When Rose eventually obtains public insurance, she is automatically assigned to a primary care provider (PCP). Upon their first meeting, Rose reports to the new PCP that she thinks her mom carries similar symptoms of bipolar disorder, which seem to have worsened after she experienced a near-death event during an earthquake in Haiti. During this visit with the PCP, our patient becomes tearful when asked to follow up for routine age-appropriate screening. She reports that last year, while hospitalized for a flare-up of her bipolar disorder, she was forced to take new psychiatric medications without her consent that sedated her for several days. Traumatized from that experience and reflecting on her mother's experience, she explains to the new PCP

Figure 1. Nested model of transition-age youth
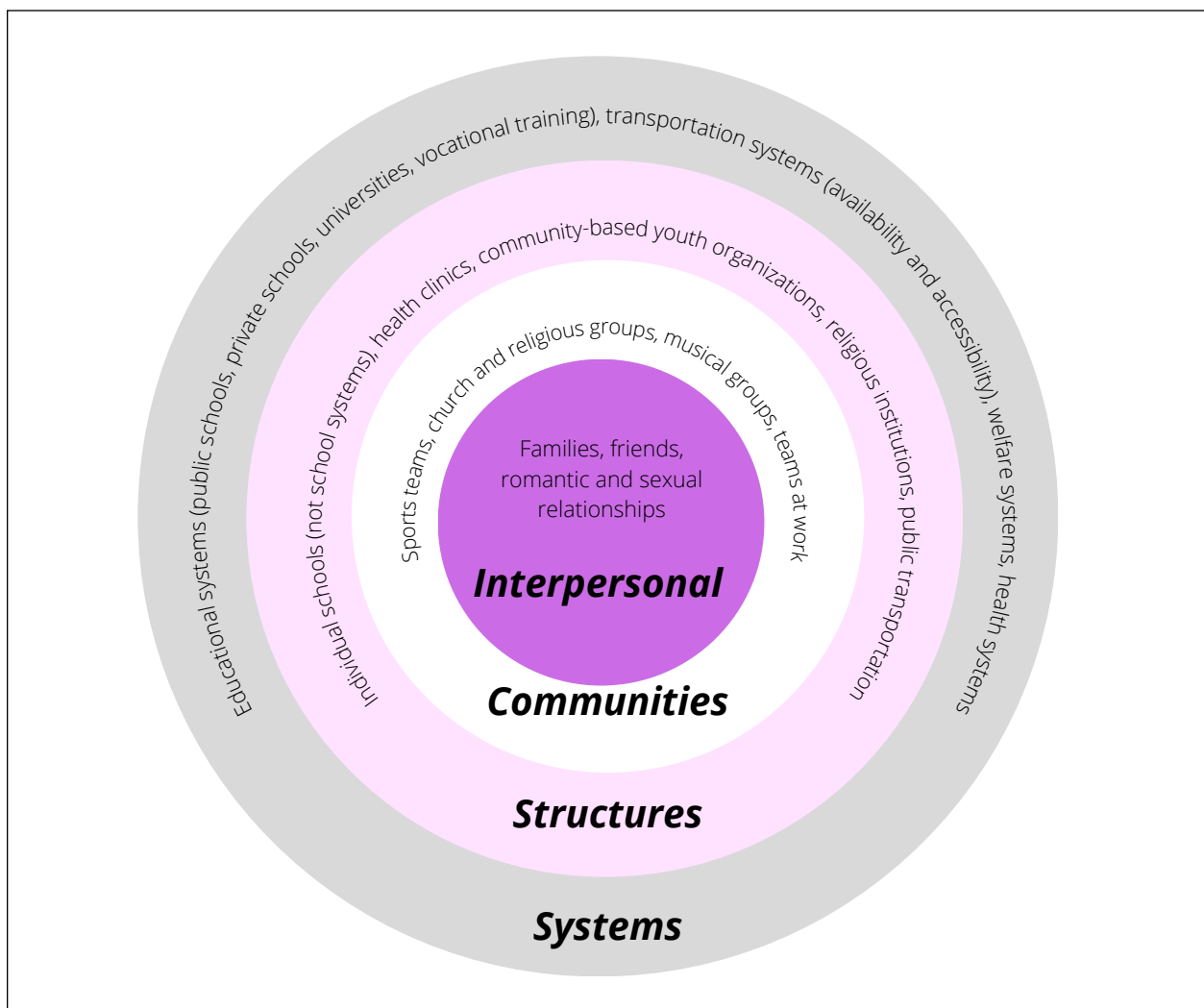
her mistrust in the system. She indicates her desire for the PCP to understand the cultural perspective from which she is coming. The PCP, a white woman, explains that the treatments she wants Rose to get are different and not sedating, but leaves the choice ultimately with our patient. The PCP is quick to cut Rose off and gets easily frustrated with her resistance. Rose eventually agrees, but becomes overwhelmed shortly after leaving the office. Unsure of what to do, she signs into her patient portal and reviews the medical encounter written by the PCP, which states, "Patient has been non-compliant and non-adherent to recommendations." Rose is hurt and overwhelmed and decides not to follow up. Several months later, she has a syncopal episode at work and gets admitted to a different hospital for complications from her diabetes. Missing work for being hospitalized, she gets fired from her job and after discharge further struggles to follow up for primary care.

Case from Ghana: Neurodiversity and transition

Kofi, a 17-year-old Ghanaian boy with tuberous sclerosis complex (TSC) and epilepsy, presented to a transition clinic in Kumasi at a large academic teaching hospital. Kofi was diagnosed with epilepsy at the age of five and was referred to the pediatric neurology clinic of a teaching hospital at age 13 after many years of poor seizure control. He is the last of four children, with no family history of seizures or TSC. He started at a mainstream public school in rural Ghana at age four, where he entered preschool. He struggled with kindergarten, which he repeated twice, and was promoted to grade one at age seven. In the first grade, Kofi demonstrated severe difficulties in all aspects of learning due to complications from his illness; he repeated this grade twice, and then his parents withdrew him from school at age nine. Teachers' reports from the five years that he was in the mainstream educational system indicate that he struggled with all aspects of learning. However, he did not receive any referral for assessment by either an educational or a clinical psychologist. He had, however, been seen by various traditional, religious, and herbal practi-

tioners, with no improvement in seizure control or intellectual functioning. However, due to colonial notions of health care, and concern about bias, the family did not tell the neurologist that they were seeking care from community healers.

On referral to the pediatric neurology clinic at age 13, Kofi had overt cutaneous manifestations of TSC, as well as neurobehavioral challenges. He has since been seen by a clinical psychologist and diagnosed as having an intellectual disability. He has also undergone various tests, including an electroencephalogram, neuroimaging, an echocardiogram, and a renal ultrasound. His medications have been changed, and his seizures have now stabilized on two anti-seizure medications: carbamazepine, which is covered by the national health insurance scheme, and clobazam, which the family must pay for out of pocket. He occasionally has breakthrough seizures when he runs out of clobazam due to financial constraints. At age 15, Kofi was seen twice at a newly established pediatric-to-adult transition clinic and was transitioned to the adult neurology service but missed his appointment twice because his mom did not have money for transportation.

Case reflection

The literature suggests that individualized transition plans allow for unique attention to readiness as dictated by developmental milestones.[31] The above examples highlight subjects whose intersectional identities have consequential similarities and differences across systems and structures globally. Trauma was experienced in both cases at the personal, systemic, and structural level. Despite their geographic disparity, both cases also sit at the intersection of "Western" and traditional medicine, which ultimately promotes more fragmented than holistic care. The two cases also illustrate the need for multisectoral collaboration. In thinking about our adolescent with TSC, would his case have been different if the health sector and the education sector had been able to collaborate? Furthermore, while not specific to HCT, our case illuminates the failure of health systems to support chronic care. These are issues that are particularly integral to

HCT but pose challenges across many domains of health. What if there were a direct referral system or collaboration between traditional and spiritual healers, on the one hand, and neurology or pediatrics, on the other? In our first case, how would the patient have benefited from a trauma-informed approach that embeds mental health care into the pediatric-to-adult transition process? What would have been different if Haitian healing practices had been invited to be discussed during her visits with her PCP? How could both cases have been different if the insurance schema in both countries recognized intersectional disparity and supported these patients specifically at these vulnerable life periods? Though both patients may have been included on transition registries and transitioned according to policy, and providers may have given "warm handoffs," it is critical to recognize how without intentionally integrating anti-racist, anti-colonial, anti-oppressive care, the health system is built to increasingly marginalize those already on the periphery.

Reimagining structurally competent rights-based and humble care for transition-age youth

Children born with once rare pediatric-onset disease are now living into adulthood in striking numbers. But what does that mean if we have not created structurally safe health systems for them to age into? As a collective, we used themes generated from our conversations to create pillars of what we would imagine to be a structurally supportive system and explored those pillars by developmental period (see Table 1). We then applied the PANEL framework to these pillars utilizing examples from the cases discussed above (see Table 2). Our goal is not to impose Western visions on transition medicine through human rights practice but rather to engage in the effort to produce structurally equal transition medicine as one that asks of us "pragmatic solidarity." Solidarity is not only a *felt* practice (empathy by HCT providers) but also a material one in which we contribute *materially* (where systems and structures are built to protect

those most at the periphery during this process) what we can to common cause.[32] These practices would also be grounded in the understanding that the needs of patients vary greatly among contexts. These alternative structures would represent three pillars, as outlined in Table 1:

1. Recognition of the importance of opt-out culturally and structurally humble *mental health* care, with a focus on healing justice and social capital. It is well known that adolescents are at increased risk of mental health morbidity and that those with ongoing chronic illness are at even higher risk. Supporting holistic well-being prophylactically by building community and enhancing sense of belonging can strengthen resiliency during this developmental period.

2. *Multisectoral integration*, including non-health-related sectors, in which practitioners center individuals' holistic developmental milestones, such as school, jobs, and relationships. This structure also recognizes and names the shame and strife that is inherent with being chronically ill, in pain, and feeling "left out" of adulting experiences.

3. *Transition readiness with an intersectional lens* that supports championing at the individual and systemic level to overcome intersectional oppression. Validating this health-seeking behavior looks different in different settings, and therefore the health system must adapt to meet the patient where they are.

The PANEL framework highlights areas of further growth in transition medicine in the domains of participation, accountability, nondiscrimination and equity, empowerment, and legality.

Participation. Though not often the case in clinical medicine, transition medicine relies on iterative feedback from patients and families in process metrics. However, to further decolonize our practice, it is also critical that diverse providers—including traditional, religious, and spiritual healers—have input into transition processes. How can we create systems so patients, providers, and community members are able to actively partici-

pate in a way that works for them? How can this be done from a population perspective? In some contexts, virtual platforms for patient care have allowed for nimble and flexible care.[33] This enables the clinic to meet patients and families at their home, where providers can meet pets or family members or see their gardens or artwork, for example, all of which promotes human-centered care. Alternative learning styles can be honored utilizing different platforms within virtual features. However, with globally unequal access to digital technologies, these approaches can be limiting for patients and families who lack access to this technology. In other contexts, other proven interventions such as community health worker programs and regional clinics may be more helpful. Patient advisory committees also serve as a dynamic way to promote care that is responsive to adolescents and young adults, built with the understanding that these committees should demographically represent the communi-

ties that clinics serve.[34] Additionally, integrative approaches that accept various models of non-biomedical approaches to medicine juxtaposed with biomedicine are key. These could include patient co-referrals, collaborations between orthodox and traditional medical practitioners, and the creation of a unit for traditional medicine and healers in Westernized hospitals and clinics. Incorporating aspects of traditional healing in the training of health care practitioners and creating a space for knowledge sharing have also been proposed.[35] These strategies are not a silver bullet, given the asymmetries in access to material resources and institutional recognition, as well as the marginalization of Indigenous beliefs and practices, that often shape contemporary health care systems.[36] Assuming that many communities practice syncretic healing practices, how might transition programs—and all health programs—guarantee the right to pursue culturally concordant, structurally supported care?

TABLE 1. A model for structurally supportive aging into adult-based care for young people with pediatric-onset disease

	Infancy	Childhood	Adolescence	Young adulthood
Mental health care	Interventions focused on contextually appropriate support and community building for caregivers and for infants with chronic illness	Community building that normalizes different abilities in school-age children and that continues parent-, family-, and guardian-centered support	Transformative justice models for adolescents that include community-based collective care, peer interaction, mobile technology, and psychosocial support groups; integrative care models that incorporate mental health care into primary and sub-specialty care	Avenues for young adults to share their own lived experiences with caregivers of infants with similar disease patterns (who are newly diagnosed); continuation of peer support and community engagement; integrative care models
Multisectoral integration	Clear and effective pathways for communication with multidisciplinary teams about support for tertiary and specialty care	Integration of early childhood education into care plan; clear and effective pathways for educators, mental health providers, and clinical providers to collaborate	Discussion of non-Western healing techniques (in addition to Western); inclusion of spiritual, religious, and community healers in care plan; continued collaboration with educational sector	Incorporation of care team into work or postgraduate schedules so that it centers the livelihoods of young adults; integration of policy and advocacy around issues concerning drug formulary and health coverage
Transition readiness with intersectional lens	Validation and recognition of historical and generational trauma during all touchpoints with the health system	Utilization and adaptation of transition-readiness assessments that have been co-created with patients and families with a variety of marginalized identities, understanding the nested contexts that adolescents and young adults live within	Co-creation of transition-readiness goals with the patient (and caregiver) centering what they want future providers to know about what is important to them, how they learn best, how they receive information best	Invited reflection on the transition process, with clear pathways on how to give feedback to providers; if possible, support to other younger patients from similar disease streams

Ultimately, the point is that fostering participation must be done with intention.

Accountability. How do we create systems in which providers are accountable to their own bias? How do we promote self-reflection around the types of patients who often remain in pediatric-centered care versus the ones who are encouraged to transition because of divergent non-dominant identities? Part of the solution requires the implementation of enforceable, measurable, and consequential systems-based policy. Though transition policies are a commonly accepted methodology, what is often missed is the importance of accountable structures to promote equity (and stopgap inequity). Without

this, these policies promote inequity. In Kumasi, Ghana, many successful transitions from pediatric to adult care employ the use of joint adult and pediatric clinics to assess these factors and address deficiencies that are identified.[37] This allows both adult and pediatric providers to physically attend to the patient at the same time, improving care coordination, rapport, and trust toward the new providers. It also allows for more meaningful goodbyes to pediatric providers. This is a context-driven solution, as Ghana's National Health Insurance Scheme allows for two providers to collaborate, whereas in the US system, that would make for a challenging billing paradigm. We could, however,

TABLE 2. Rights-based framework applied to the three pillars of structurally safe transitions of care

	Mental health care	Multisectoral integration	Transition readiness with an intersectional lens	Rights-based methods (examples from cases)
Participation	Patients, families, and communities defining what "optimal mental health care" looks like	Community- and patient-driven responses to care (including traditional, religious, and spiritual healers) with regard to how they are integrated within care teams	Dynamic praxis cycle gathering information from youth with a variety of non-dominant identities and their experience with transition	Case 1: Asking Rose to describe what would make her feel most supported in terms of her mental well-being and her physical health Case 2: Including the participation of traditional healers in the transition process
Accountability	Metrics for health systems evaluating the provision of community-driven mental health care	Metrics and enforcement of intersectoral collaboration (e.g., % of clinical providers collaborating with non-Western healers, school-systems, employers, etc.)	Metrics to ensure that different identities are supported and captured (e.g., multiple ways of communication for neurodiverse individuals, social and financial support)	Documentation in patients' medical records explicitly stating structural vulnerabilities and how they are being addressed, and asking future providers to address each in the same way they would address "clinical" issues
Nondiscrimination and equality	Supporting and promoting "last-mile" mental health care for the most vulnerable	"Opt-out" age-appropriate mental and physical health screening (across disciplines) to ensure holistic care	Promotion of active identification of non-dominant identities with tiered support across sectors	In both cases, specifically naming multiply marginalized identities and how they interact with the health system; for example, "Rose self-identifies as Haitian-American, Black and female, and it is important to view her perceptions of health and well-being from these perspectives"
Empowerment	Normalizing and validating mental health care for this population in a way that promotes self-advocacy and self- and community-efficacy	Adolescents and young adults feel empowered to ask for and engage in multidisciplinary care peri- and post-transition	Transition-age youth with non-dominant identities whose identities are not being met by the health system are empowered to mention this to providers	In case 2, asking caregivers to design or articulate the transition process in a way that feels most approachable for them and their family; documentation of that method and use of accountability structures to promote a patient- and family- centered response
Legality	Enforceable, measurable laws and policies that support equal access to affordable, quality mental health care	Cross-sectoral policies promoting and allowing for communication and collaboration	Political accountability for accessibility (e.g., allowing for multiple modes of engagement, physical accessibility for hospitals, etc.)	In both cases, advocating for policies that do not allow abrupt insurance or financial transitions at vulnerable developmental periods (adolescence and early adulthood)

imagine transforming the formal systems of payment to enable such care innovations.

Nondiscrimination and equality. Critical to enforcing this element of a rights-based framework is intentionality in the type and method of data collection. How are we creating transition registries? What data points about systemic bias and systemic oppression are being collected? When our patient with TSC in Ghana fails to transition, how are we capturing the financial burden of his antiepileptics that allowed him to begin to seize again? We recommend, in this vein, a registry with intentional equity indicators, attuned to the potential disparities in health care and access to care, not to mention lived experiences of care. It is important to build on existing structures while also recognizing the context within which they are practiced. Pediatric specialists should be encouraged to find transition-readiness assessments based on context-appropriate developmental readiness, disease stability, and sociocultural and economic factors.

Empowerment. Building social capital through community has been shown to support rights-based practice for healing. Christian Ntizimira refers to Ubuntu (*umuntu ngumuntu ngabantu*) as the African expression of "who we are" as a critical message for decolonizing end-of-life practice, through a shared community. Transition medicine benefits from similar decolonized ideals, where social capital can be pivotal to promote wellness, and community can be used as a resource for justice. We recommend youth-led psychosocial support groups that build community and help youth connect through shared experience.[38] Chronic disease can be isolating and stigmatizing in many settings, and coming together to share experiences can be empowering and build protective factors in promoting well-being.

Legality. It is critical to discuss the Convention on the Rights of Persons with Disabilities when thinking about the legality for structurally safe care for this population. This convention, signed by both Ghana and the United States (but which only Ghana has ratified), centers on the aim to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."[39] Using this as groundwork, it is imperative that there be legally binding policies that promote equity in access to care. Legal frameworks involving the voices of clinicians (both Western and non-Western) and patients must be advocated for before local, regional, and national governments. Important points for advocacy include supported decision-making, equity in medications on national formularies, and accessible health services for people with varying abilities.

Conclusion

Current definitions and accepted best practices of the health care transition from pediatric to adult care fail to intentionally recognize the diverse needs of adolescents and young adults with multiply marginalized identities and the overwhelming impact of racism and colonialism on HCT. In our experience, the current standard of care for practicing transition medicine promotes harm. We believe that the transition process should instead be viewed through three pillars—supportive peri-transitional mental health care, multisectoral collaboration, and transition readiness with an intersectional lens—in order to guide providers, systems, and structures toward equitable, safe, and holistic care for these populations. We hope that this model can promote the use of an actionable rights-based methodology in the field of transition medicine to facilitate more just and equitable HCT.

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Social Accountability and Legal Empowerment Initiatives: Improving the Health of Underserved Roma Communities in Eastern Europe

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Abstract

Improving the protection of the right to health of ethnic Roma people is one of the most pressing public health challenges in contemporary Europe, as their life expectancy and health status remain significantly lower than their non-Roma counterparts.[1] This paper analyzes Roma-led accountability initiatives that embrace social accountability and legal empowerment approaches to advocate for equitable fulfillment of the right to health. While these initiatives have led to the elimination of some harmful health practices (such as illegal cash bribes and violent and abusive treatment by medical professionals) and to improvements in health care, and some Roma communities have become driving forces for local and national health system reforms for advancing the fulfillment of health rights, the health inequalities affecting Roma communities remain significant. This issue also remains largely overlooked by European health research and policy experts, who are mostly reluctant to incorporate analyses of ethnicity and racialization into their research on health inequalities in Europe. The COVID-19 pandemic has further exacerbated these health inequalities.

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Introduction

The quality, affordability, and inclusiveness of health care systems is determined by social practice, and structural factors such as environmental pollution and climate change, political and economic policy, access to public infrastructure, childhood development and education, poverty, and housing are fundamental determinants of health.[2] Systemic racism and discrimination mean that these factors impact particular communities inequitably, and thus they influence health, disease, and medical practice.[3] They make people less protected and more exposed to malpractice. The recent COVID-19 pandemic reinforced the impact of racism and discrimination on health.[4]

Numbering around 12 million, Roma people are the largest ethnic minority in Europe. They are also the most disadvantaged ethnic minority in the region as a result of antigypsyism.[5] Antigypsyism remains among the most conventional, unapologetic, and blatant forms of racism and ethnic discrimination in Europe.[6] Despite political commitments made by European governments and the European Union (EU), progress has been limited in reducing the avoidable and unnecessary health inequities and discrimination in health care endured by Roma people. They continue to be disproportionately burdened by chronic and preventable diseases, excluded from prevention programs, underserved by health systems, and they often die young.[7] Their life expectancy and health status remain significantly lower than their non-Roma counterparts in all European countries.[8] Their health insurance coverage has steadily worsened, as has their subjective experience of exclusion from or unequal access to health care.[9]

The scarce evidence on the effectiveness of interventions aimed at closing the gap between Roma people and majority populations in health outcomes is due to the reluctance of many European governments to collect ethnically disaggregated health data.[10] These states defy the recommendations of the United Nations and the European Commission and fail to follow up on smaller-scale studies by universities and civil society.[11] Indeed, despite the often alarming results of these studies, the health status of Roma people remains mostly ignored by European policy makers and public health professionals.[12] The relative lack of data compounds other factors determining health status, such as continuous political instability in some EU member states; austerity measures in health care, housing, and education; and ethnic prejudice and racism on the part of medical professionals. According to the World Health Organization, accountability, participation, and equality and nondiscrimination are three main principles of the human right to health.[13] This right also includes access to credible, locally generated evidence on issues with health service delivery.

In this paper, we focus on the decade-long mostly Roma-led initiatives to confront inequalities in health care provision in Romania, Bulgaria, and North Macedonia. These initiatives have led to Roma civil society's increasing voice and representation in decisions concerning the quality and availability of health care services; the affordability and accessibility of health insurance; the availability of health education and prevention programs focused on childhood vaccinations, sexual health, and reproductive health; and living environments and public infrastructure. These initiatives have been driven by a conviction that building local capacities to collect and analyze evidence on the implementation (or lack thereof) of health policies and services in Roma communities will not only limit some harmful practices but also equip these communities with skills to further advocate for their right to health. The initiatives have been clustered around two main conceptual and methodological approaches: social accountability and legal empowerment.

Conceptualizing social accountability and legal empowerment

Social accountability is an evolving umbrella concept to promote civic engagement in order to hold governments accountable to their policy commitments. It employs a combination of tools, such as community monitoring and oversight of public and private sector performance, user-centered public information systems, public complaint and

grievance redress mechanisms, and citizen participation in resource allocation decision-making, such as participatory budgeting.[14] It covers strategies developed in the last two decades to pressure institutions and their governing structures and to demand fairer, more effective, and more responsive public services.[15]

Some of the key elements of social accountability are as follows:

- mobilizing and empowering people to make demands related to community priorities rather than to individual grievances;

- advocating and interacting with the state through "public space" and public deliberation;

- focusing on public goods and systemic problems, including resource distribution, failures in ensuring rights, and limited participation in policymaking;

- triggering formal sanction mechanisms and the imposition of political and reputational costs on responsible public authorities; and

- working fully with other strategies, such as policy advocacy, public planning, and cross-cutting alliances.[16]

Social accountability requires that people focus on and prioritize specific policies or programs, be trained in data collection, and be supported by experts to request and receive relevant policy documents. It also requires that public authorities be incentivized (by possibilities of formal sanctions or reputational costs) and formally committed to respond to the members of society. Social accountability approaches are often accompanied by approaches to increase the legal capacities of vulnerable communities to seek legal redress.

Legal empowerment is rooted in a human rights-based approach to development, which recognizes that poverty results from disempowerment, vulnerability, exclusion, lack of information, and discrimination.[17] It seeks to cultivate the agency and power of affected communities, provide practical and concrete solutions to legal problems, and employ paralegals and other non-lawyer professionals to support and educate lawyers about problems faced by vulnerable communities.[18] Some researchers conceptualize legal empowerment as "the transfer of power from the usual gatekeepers of the law—lawyers, judges, police, and state officials—to ordinary people who make the law meaningful on a local level and enhance the agency of disadvantaged populations."[19] The concept includes a variety of tools: legal awareness-raising, legal service provision, mediation services and dispute resolution, law reform initiatives, and litigation. These tools aim to increase legal literacy and provide individual legal capacity to understand and use the law without creating an over-dependency on lawyers.[20]

Community paralegals are often grassroots advocates who use their knowledge of the law to seek concrete solutions to local instances of injustice.[21] Equipped with legal and administrative knowledge, community paralegals—in some instances supported by lawyers—can facilitate access to government agencies and mobilize their communities to attend to the human rights issues around them.[22]

Some of the key elements of legal empowerment are as follows:

- empowering members of affected communities vis-à-vis their legal rights invoking existing legal regulations;

- focusing on rights violations and the structures that perpetuate them (the starting point is usually the individual, though systemic problems may be addressed);

- providing legal expertise and capacity to mobilize the community;

- enabling direct redress of grievances and potentially triggering changes in law and policy; and

- working with other strategies, such as policy advocacy and community organizing.[23]

The main advantages of legal empowerment approaches are that they enable people to understand and apply laws and administrative rules and procedures related to their social welfare, housing,

education, and health rights, and they can lead to legal precedents that formalize and solidify policy change or that sanction an inefficient or discriminatory practice of service provision.

Social accountability and legal empowerment are also effective approaches for aligning the priorities of civil society organizations with the needs of their communities. However, the adoption of these approaches can be challenging, as it requires significant investments of human and financial resources over the long term. These approaches also presuppose that structurally vulnerable communities, while pressured by multiple deprivations, prioritize and strategically focus on a limited number of issues. Another challenge is bridging the local-national gap and translating local efforts into effective and transformative policy change. Although some studies have found that social accountability and legal empowerment can positively influence governments and other institutions, the most cited impact remains local.[24]

The public institutions most often targeted with social accountability and legal empowerment initiatives are those responsible for overseeing service provision in education, health care, infrastructure, and public works, including access to food and water.[25] Health-related social accountability and legal empowerment approaches often focus on monitoring health service delivery (e.g., informal payments requested by doctors, number of births at health facilities rather than at home, child health visits, immunizations, and community nurses) over time. The most developed body of work on social accountability approaches in health comes from Sub-Saharan Africa (specifically South Africa), Latin America, Indonesia, and South Asia. In structurally vulnerable communities—from Dalit communities in India to Indigenous communities in Guatemala—social accountability has served as a powerful vehicle to inform communities about their health rights and stimulate their involvement in advocacy to improve health services in their localities.[26] The impetus to mobilize and organize has stemmed from realizing that although the law mandates the provision of certain public health services,

these services are not provided for these communities, or they are being provided in substandard or unevenly distributed ways. The goal of social accountability in vulnerable communities is to increase health care access by systematically recording malpractice and the lack of equitable access, as well as by organizing to demand compensation and improvement.

Targeting malpractice and the absence and poor quality of health services for Roma people in Europe

Coercive treatment and other violations of patients' rights to consensual treatment and confidentiality can break people's trust in health care systems. It has been pointed out that racialized groups experience this medical malpractice and abuse more frequently.[27] Moreover, with limited awareness about health care provisions and social benefits, these communities remain sidelined from many aspects of public life, including access to quality health care services.

Since 2010, in partnership with Roma civil society, the Open Society Foundations has supported citizen-based accountability and legal empowerment initiatives designed to advance health and human rights, challenge discrimination, and improve access to quality health care services for Roma people in Eastern Europe. The initial interventions initially focused on legal empowerment. However, it was soon acknowledged that legal empowerment, in which a majority of cases deal with individual situations, needed to be complemented with community-level accountability-focused organizing.[28] The combined approach of social accountability and legal empowerment was thus piloted for the first time in the case of European Roma people.[29]

In 2011, the first convening on social accountability in Roma health was organized. At the event, social accountability experts from India trained Roma activists from the Western Balkans, Romania, and Bulgaria. Additionally, a pool of activists attended trainings delivered by experts from the Public Service Accountability Monitor Initiative of

Rhodes University in South Africa and the University of Washington. In 2013, a regional network of Roma civil society and expert partners was established to support peer learning.[30] That same year, a new strategic focus on narrative change that aimed to challenge stereotypes about Roma people by health care professionals was implemented.[31] These new relationships and networks contributed to developing an international body of knowledge on social accountability and community monitoring, such as the Community of Practitioners on Accountability and Social Action in Health, to which Roma civil society organizations and experts have actively contributed.

These initiatives supported Roma civil society organizations in determining their approaches and adjusting them to their local contexts in the emerging Roma health field. While organizations in North Macedonia chose to focus collectively on specific issues such as immunization, those in Bulgaria and Romania chose to focus on a range of issues based on the prioritization of each community. Among these issues were illegal and informal cash bribes requested by medical professionals, access to the package of free medical services guaranteed by the law, access to pre- and postnatal care, and immunization coverage.

These social accountability and legal empowerment initiatives developed differently in different national contexts. In North Macedonia, the Association for Emancipation, Solidarity and Equality of Women (ESE) provided technical and methodological support for grassroots Roma organizations, including KHAM, National Roma Centrum, Initiative for Development and Inclusion of Communities, Romano Chachipe, Sonce, Association of Citizens and Educators for the Protection of the Rights of Women and Children, Association for Legal Education and Transparency, and Health Education and Research Association (HERA).[32] In Romania, it took longer for this approach to gain traction, largely because the Open Society Foundations initiative's inflexible conceptual and methodological design had ineffectively harvested local inputs. This approach eventually antagonized some of the more established Roma civil society

organizations. Moreover, after Romania joined the EU in 2007, some Roma organizations began implementing large, administratively intense, EU-funded social service delivery projects and thus complemented state services. Finally, a dozen grassroots Roma organizations collaborating with Open Society Foundations were not confident that they could develop in-house expertise in conducting surveys and monitoring local health care policies and budgets without technical support. The Institute for Public Policy, a national watchdog organization, eventually stepped in to provide technical assistance, but this collaboration was short-lived as the organization went through a leadership transition and shifted its focus to the implementation of EU projects. As a result of largely top-down approaches and insufficient investment in building trust by donors, some Roma grassroots organizations did not fully embrace the hybrid approach of social accountability and legal empowerment, even after receiving training and technical support, and returned to social service delivery. Some organizations focused on addressing immediate individual needs through legal aid assistance, while others engaged in collective action based on existing health policy. The organizations piloting these approaches in Romania were O Del Amenca and APIS, which were Roma led, and Resource Center for Public Participation, Foundation for People Development, and Together for Them, which were non-Roma led. Despite the objective to support and develop Roma leadership, the abovementioned challenges, together with rigid, top-down methodologies applied by donors, resulted in a mixed composition of partners while some established Roma organizations withdrew their participation. In Bulgaria, several Roma civil society organizations with advocates in communities across the country (e.g., Largo Association, Center Amalipe for Interethnic Dialogue and Tolerance, World Without Borders, Thirst for Life, and the Diverse and Equal Association) adopted the hybrid social accountability and legal empowerment approach. Amalipe then offered technical support for grassroots initiatives such as the World Without Borders operating in the Stara Zagora region and the Largo Association based in

the Roma neighborhood of Iztok in Kystendil. These partner organizations have since become well-recognized advocates for advancing health in their regions. Each organization has conducted regular community monitoring and evidence collection on health and social status and has used these data to evaluate policy implementation.

One of the most important cross-national outcomes of these initiatives has been the development of a more intense, and in some instances positive, relationship between affected Roma communities and local health authorities, which has resulted in the elimination of harmful practices and improved delivery of routine health services. Furthermore, authorities have begun to share information with Roma communities more transparently, which has led to a decrease in freedom of information requests regarding their health status and health interventions. Finally, the initiatives' focus on relationships based on mutual recognition, evidence-based consultation, and community outreach has resulted in some public authorities adopting social accountability or legal empowerment approaches as a formal mechanism for monitoring the impact of their health policies. Below, we explore the main lessons learned from these initiatives.

Increasing accessibility and eliminating malpractice

The combined approach has been effective in challenging discriminatory and harmful practices, such as informal payments, violent and abusive treatment by medical professionals, and child pregnancy and early marriage. Community organizers and civil society organizations have documented and reported many cases of disrespect, abuse, and systemic lack of communication on the part of general practitioners, dentists, gynecologists, and other specialized medical staff when treating Roma patients. In some instances, organizers and civil society organizations have also pursued strategic litigation.[33] The most common forms of malpractice identified include illegal payments imposed on Roma patients by medical professionals, unavailable dental care and other specialized services, and misinformation and coercive requirements for

accessing health insurance, all of which limit their access to health services.[34]

In North Macedonia, KHAM in Delchevo has developed a constructive relationship with the gynecologist in their area, persuading her to increase the number of patients on her roster instead of charging illegal payments. Similarly, the Roma Women Association in Shuto Orizari and HERA have logged instances of requested illegal cash bribes, pressuring doctors to stop asking for these payments, while at the same time educating and accompanying local Romani women to ensure that they are not charged. Informal payments have been reduced significantly over time as a result of these efforts. Notwithstanding these examples of progress, and despite each country declaring universal health care coverage, large numbers of Roma people lack health insurance due to administrative hurdles and payment requirements.[35] In North Macedonia, KHAM successfully challenged a state practice of disqualifying from health insurance Roma people who unknowingly did not submit information about their income, which had resulted in criminal charges against Roma and other marginalized groups.

Another example of community-led action to establish missing specialized services is the provision of a dental cabinet for rural, majority-Roma communities in an area where there had been no dental services for several decades. Amalipe has gradually expanded the initiative by providing technical assistance to other civil society organizations and informal groups in 12 communities in all six regions of Bulgaria. It has also been leading advocacy efforts to introduce community monitoring as one of the formal monitoring and evaluation mechanisms for the National Roma Integration Strategies.

Furthermore, the majority-Roma community of Crnik in North Macedonia successfully mobilized to make services available from the general practitioner (GP) in their community. They organized to enact their right based on a regulation that stipulates that a municipality of their size should have a GP available in the community at least three days per week. With the support of

KHAM, which provided health education and helped local activists analyze the legislation and collect relevant documents, they submitted a petition to local authorities, resulting in a decision to approve a visiting GP service. Similarly, the Initiative for Development and Inclusion of Communities, Romani Chachipe, HERA, and ESE successfully lobbied the government to establish a gynecological clinic in the Roma neighborhood of Shuto Orizari in Skopje.[36] However, the new gynecologist began imposing informal payments, so the community mobilized again, and the graft payment practice was abolished.[37]

In our decade-plus experience exploring the best models of mobilization of Roma communities around health rights, we have discovered that in order to bring about structural change, there also needs to be a collective focus on accountability. Without such a component, mobilization efforts risk resulting in a continuum of random unsustainable administrative fixes. There is a need for strong community ownership in defining and rectifying harmful and discriminatory health policies.

Transparency and evidence-driven action

Doctors, nurses, and pharmacists routinely fail to provide adequate explanation to Roma patients about their medical conditions, and as a result, many patients with chronic diseases are unaware of their need for regular checkups. The work of Roma community paralegals and health mediators has resulted in improvements in health education among Roma communities, as well as in cultural competence among medical professionals.[38]

The advantage of the combined approach is that paralegals are recruited from communities to which lawyers might have limited access. Evidence from Romania and North Macedonia demonstrates that the availability of paralegal services in Roma communities substantially increases their ability to pursue legal claims related to health rights.[39] The paralegal sessions have been widely attended by community members, including both Roma and non-Roma people, who face challenges in the recognition of their rights as patients. This legal mobilization effort has become a source of integra-

tion and solidarity, especially in countries where public health systems are weakening or collapsing.

The focus on community-based accountability has enabled Roma communities to review how public health authorities implement formally declared commitments in their communities while at the same time placing the communities in constructive and evidence-based dialogue with authorities, often mediated by civil society organizations. When discrepancies between commitments and implementation have been identified, communities engage in evidence-based advocacy with relevant public authorities directly responsible for policy.

In Romania, Roma-led initiatives have succeeded in collecting relevant evidence on health inequalities endured by Roma people, which has been used in local negotiations with health providers and to contribute to national and European policy.[40] For example, during a measles outbreak in 2018, there were 64 deaths reported, including 58 children. All cases were from regions with large Roma communities that were insufficiently immunized. The Together for Them association, based in Cluj, mobilized the local Roma community living near a garbage dump on the outskirts of Baia Mare to demand their right to immunization. As a direct outcome of the association's work, immunization coverage, which had previously been below 50%, rose to over 60% in one year and continued rising thereafter.[41]

In Bulgaria, through door-to-door outreach, Roma civil society organizations have mobilized communities to identify and monitor health-related problems, tracking and documenting progress or lack thereof. They also support informal community-based groups in engaging in advocacy with local health care stakeholders. They have developed a system of citizen report cards (participatory surveys to grade public services), community score cards (compiling information on community experiences with public services based on focus group discussions), and social audits (community assessments of public records and on-site assessments of the utilization of public resources). Such monitoring has assisted Roma advocates in making evidence-based arguments to demonstrate system-level failures and

in engaging with those in power to enact measures to address these failures. Among the most common issues that have been raised are graft payments, health insurance inaccessibility that limits access to health services, and lack of dental care and other specialized services. Organizations have addressed some of these issues directly, such as by identifying an eye care provider to offer consultations and provide glasses at reduced prices, while other issues have required more systematic engagement in terms of community awareness and advocacy.

The work of the Largo Association in the Roma neighborhood of Iztok in Kyustendil, Bulgaria, has also been acknowledged by national and international actors. Its community moderators have conducted regular community health status monitoring as a result of an annual action plan developed in partnership with the regional health inspectorate. Most of the association's outreach work has addressed sexually transmitted infections, immunization, and maternal health, as well as the implementation of a public ordinance that allows free gynecological examinations for pregnant women from socially excluded communities. These priorities emerged as outcomes of frequent community consultations and monitoring. For example, when the Largo Association uncovered the practice of Romani women being rejected from the free prenatal care appointment for uninsured women that is mandated by law, it worked together with the regional health care inspectorate to provide guidance to medical practitioners and enforce this right. It has also developed a productive relationship with the local hospital, resulting in increased satisfaction among Roma patients.[42]

In North Macedonia, ESE has developed a close working relationship with health authorities that enables channeling evidence collected by local Roma organizations, and their recommendations, directly to the North Macedonian government.

The evidence collected through community monitoring, budget monitoring, and social audits has fed into different policy monitoring and evaluation reports, including the review of the implementation of the national Roma inclusion strategies of the European Commission.[43] Conse-quently and quite uniquely, some EU documents and some national documents include data collected and interpreted directly by marginalized Roma communities in Bulgaria, Romania, and North Macedonia.[44]

Policy advocacy and adoption of approaches by public institutions

Roma-led initiatives have led to some cases of the institutionalization of community-led accountability efforts while preserving some degree of their watchdog capacities and professional independence.

In North Macedonia, several civil society groups set a common priority of monitoring the implementation of the National Program for Active Care of Mothers and Children and the National Prevention of Cervical Cancer Program. By documenting patterns of issues in terms of access to health services among Roma women and children in different parts of the country, the organizations were able to demonstrate that these are not isolated issues and to advocate for systemic health care reforms to eliminate the inequities experienced by Roma communities. The organizations identified key barriers faced by Roma people in accessing benefits and services provided by national programs and served as bridges between communities and health care professionals. One of the main outcomes of their work is that these national programs have introduced specific commitments to conduct educational sessions for vulnerable groups, including Roma women, with an associated budget allocation. The organizations have also managed to push for health budget increases for vulnerable communities. Moreover, with the support of HERA's informal group of Romani women from the Skopje neighborhood of Shuto Orizari, the National Roma Centrum in Kumanovo has focused its social accountability work on the sexual and reproductive health and rights of Romani women in North Macedonia. One of the outcomes of this work has been the inclusion of free contraception for women from marginalized groups in the Sexual and Reproductive Health Action Plan for 2010–2020.[45]

In North Macedonia and Romania, a law is

under consideration to enable municipal funding for community paralegals.[46] Further, in 2018, the Ministry of Health and National Employment Agency of North Macedonia adopted social accountability approaches developed by civil society organizations to monitor the implementation of its health and employment programs. And the Open Government Partnership has trained its employees to partner with civil society in conducting social audits.[47]

In Bulgaria, some of the 12 community centers established by Amalipe have been receiving financial support from local municipalities since 2011. While this development has provided for more sustainability beyond private-donor project funding, it may have also affected their ability to hold local authorities fully accountable.

Obstacles to scaling up local-level interventions to national-level policy advocacy and the disconnect between the data gathered through community monitoring at the local level and the national policy advocacy priorities identified by civil society organizations remain the main challenges in the implementation of the combined approach to improving the health status of Roma communities. Many organizations have focused on meeting people's immediate needs through legal aid and individual trade-offs with local authorities, while refraining from striving for more systematic change. In this context, they have tactically opted for "liberal empowerment" that focuses on individual growth and the rational action of social actors based on individual interests, and have underexplored "liberating empowerment" as a process where those denied the ability to make strategic life choices acquire such an ability in terms of resources and agency for collective action and structural change.[48] This trend became evident when the COVID-19 pandemic hit Roma communities in 2020.

Community-led accountability during the COVID-19 pandemic

The impact and devastation of COVID-19 on Roma communities was twofold: the virus itself and the repressive, discriminatory, and double-standard emergency measures of the governments that ignored United Nations recommendations.[49] At the beginning of the pandemic, United Nations experts warned governments that their measures must not be used as a basis to target particular groups, function as a cover for repressive action, or be used to silence human rights defenders, and that state responses must be proportionate, necessary, and nondiscriminatory.[50] However, many Roma communities found themselves collectively quarantined by the army and police, with limited access to food, primary health care, and essential medicine. Elderly Romani people suffering from chronic diseases and pregnant women were the most severely affected. The supply of water and disinfectants provided at the entry points to the communities was often temporary and then discontinued after the emergency quarantine was lifted. Roma children were largely failed by education systems during the transition to online learning, as they were not equipped for distance learning (due to, among other things, a lack of access to internet, computers, and physical spaces for learning).[51]

Most local organizations and organizers promptly refocused their efforts to focus on the COVID-19 pandemic and reshaped part of their operations to humanitarian aid (e.g., in North Macedonia, where organizations implemented Red Cross services in Roma communities). During the early stages of the pandemic, they focused on ensuring that Roma communities had access to essential public health measures, such as disinfectants, testing, medicines, and vaccines, and that Roma outreach workers (health mediators, community nurses, and health emergency support staff) had access to adequate personal protective equipment. It became increasingly clear that in the context of their work, the largest challenges were misinformation campaigns and vaccine skepticism among Roma communities.

The latter became an overwhelming factor for community organizers and organizations practicing social accountability and legal empowerment approaches, as the high level of mistrust in medical interventions among Roma people—who have

historically been subjected to unethical medical experimentation—grew ever stronger in the context of repressive and double-standard approaches from governments and public health experts.[52]

Even if there is anecdotal evidence that the communities supported by organizers responded better to misinformation campaigns and demonstrated higher vaccine uptake, organizers often withdrew from high-profile campaigning due to threats and personal assaults. On the whole, the COVID-19 pandemic deepened mistrust in medical interventions and rolled back some of the previous achievements of Roma-led initiatives in the areas of social accountability and legal empowerment.

Conclusion

Social accountability and legal empowerment initiatives aim at better aligning health care system priorities with human rights and right to health frameworks. These initiatives build on and highlight the work that Roma communities have been doing regarding their right to health and channel the support of non-Roma experts (including lawyers, scholars, human rights workers, and health professionals). They also challenge structural discrimination, racism, and "antigypsyism" in health care establishments, as well as incidents of malpractice and abuse in health care facilities. By promoting Roma participation and direct input in health-related decision-making and monitoring of health programs, these initiatives also help dismantle power dynamics that lead to the exclusion of Roma people. These initiatives also increase the legitimacy of professional Roma civil society organizations because they bring them closer to and make them more accountable to their communities.

However, it is also important to recognize that the application of rigid methodologies and top-down approaches in different national and local contexts has sometimes resulted in weakened trust, the imperfect harvesting of local inputs, and the withdrawal of key Roma civil society organizations.

Many Roma people live in poor and segregated neighborhoods. Spatial segregation and social exclusion are often accompanied by substandard living conditions, including poor sanitation, a lack of public utilities, and environmental hazards (such as toxic industrial waste, garbage dumps, floods, and the intermingling of waste and drinking water), all of which adversely affect their health. Beyond addressing discrimination in access to quality health care, many Roma civil society organizations and activists are working on the issues of housing, employment, and education. In fact, they were doing this before they started working on health, and thus, from the inception of these initiatives, they recognized the important role of social determinants of health.[53]

The most transformative outcome of this decade-long effort is that European health care systems have effectively become less hostile toward Roma people. The assistance of paralegals from the Roma community has lessened the open and outright abuse of Roma patients in health care settings. These paralegals have also been successful in reducing administrative barriers and providing access to personal documents, thereby fostering individuals' access to health care.

Most of the initiatives have developed specific thematic foci on improving the reproductive health of Romani women, the immunization of Romani children, and individuals' access to personal identity and health insurance documents. Perspectives related to gender and youth have thus been central to the overall framework of these initiatives. Although we can argue that reproductive health and children's health are the most developed areas when it comes to legal mobilization around Roma health, there are mixed results, with no clear trend predicting broader structural change in these areas.[54]

While these community-organizing initiatives are well endorsed and adapted to local and national contexts, more effort needs to be made to develop collective advocacy-focused and community-driven actions that tackle structural rather than individual factors affecting Roma people's right to health. Roma people continue to be described as "hard-to-reach communities" by public health and medical professionals, and they are often portrayed as being responsible for their unequal access to health care services. Although segregation in health care facil-

ities has been legally challenged, it continues to be practiced across Eastern Europe.

Scaling up local and community-level initiatives to national policymaking and the disconnect between the evidence from community monitoring at the local level and the setting up of national-level advocacy priorities are the main remaining challenges. The focus on administrative procedures and local health care practices has been effective but has not brought about transformative change in the broader legal and policy systems. Although most organizations have developed solid skills in documenting and organizing legal cases exposing medical and bureaucratic malpractice in health care, they have yet to find a way to use this evidence to develop impactful strategic litigation and advocacy plans. In reality, grassroots organizations and community organizers have found it difficult to utilize the evidence for developing purposeful legal and policy change efforts. Moreover, focusing on meeting immediate needs through legal aid and individual trade-offs with local authorities, while refraining from striving for more systematic change, has had consequences in their communities in terms of keeping communities in a passive recipient position, while civil society organizations take on the role of service providers.

Furthermore, while community paralegals have greatly assisted individual Romani patients and been effective in helping Roma people make use of the health care system, human rights lawyers and the Roma movement more broadly have yet to capitalize on these local successes. Most of the lawsuits submitted to courts make use of criminal and not civil (antidiscrimination) laws. Most of the paralegals and health organizers prioritize mediation approaches. We argue that this is the right approach and that human rights lawyers and professional civil society organizations are structurally better positioned to engage in confrontations with the state. The paralegal work has relatively small transformative potential if strategic litigation and policy advocacy are not sufficiently employed to take up their communal work and confront the state. It is also because of the above challenges that "limited consensus remains on the effectiveness of legal empowerment interventions in optimizing health outcomes."[55]

We also recognize that limited access to quality health care services does not fully explain the gap in Roma health outcomes. The poor health status of Roma communities is significantly determined by social and environmental inequities, their living environment, and the political and socioeconomic context in which they live. Racism and ethnic discrimination would continue to determine the health outcomes of Roma people even if national health care systems were efficient. Advocates must therefore engage in efforts that go beyond the right to health and integrate all of the aspects of social, economic, and political life that determine the health of Romani people.

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The Right to Health Care Viewed from the Indigenous Research Paradigm: Violations of the Rights of an Aymara *Warmi* in Chile's Tarapacá Region

ADIMELIA MOSCOSO, CARLOS PIÑONES-RIVERA, RODRIGO ARANCIBIA, AND BÁRBARA QUENAYA

Abstract

This paper reflects on the right to health care from the Indigenous research paradigm. We analyze the case of an Aymara wise *warmi* (woman) who died after the Chilean health care system failed to provide culturally appropriate care. In the wake of her death, our cooperative launched an interdisciplinary and collaborative research project in an effort to file an administrative complaint against the family health center that treated her. We explore the events surrounding her treatment and death, as well as the institutional written response. Our work elucidates the significant differences that exist between institutional and Indigenous perspectives on what constitutes a violation of the right to health care. We demonstrate that in order to establish the existence of such violations, Aymara people are compelled to develop evidence using a naturalistic scientific and legal framework that does not coincide with their ontology. Consequently, some events and violations are not legally recognized as culturally inappropriate health care unless they are viewed through an Indigenous lens. Finally, we reflect on the problem of evidence production, specifically regarding the right to health care. We argue that the fight for the right to health care can benefit from the Indigenous research paradigm—not only for the benefit of Indigenous people but also to provide culturally appropriate care to all people.

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Introduction

They came and took her against her will using deceitful tactics. They said they would just remove some liquid and bring her back, but my mother never returned. They took her away. My mother was much happier being treated by a qulliri, someone with a great deal of knowledge developed by our ancestors. They heal people with herbs and other things.[1]

Stories like this one are part of the social memories and shared histories of Indigenous communities worldwide and are important for studies on the provision of culturally inappropriate health attention. This paper explores violations of the right to health care (considered part of the right to health) involving Indigenous peoples. We focus on the case of an Aymara wise *warmi* (woman), her family, and their community in the Tarapacá region of Chile. Doña Francisca died after the health care system failed to provide culturally appropriate care. Our analysis is based on an interdisciplinary and collaborative research project conducted by our cooperative after her death. We offer scientific and legal evidence that served as the basis of an administrative complaint filed against the family health center responsible for her care, the purpose of which was to prevent further harmful actions by that specific facility and the state.[2]

The family's testimony and the documents required to file the administrative complaint inspired two related questions regarding the Indigenous perspective. First, which knowledge system should we use to develop the evidence that allows us to identify rights violations against Indigenous peoples? Second, does the right to health care as enshrined in law include all of the dimensions appropriate for our Indigenous communities?

Reflections on the violation of human rights in health care tend to ignore both of these questions.[3] The traditional approach requires Eurocentric scientific evidence concerning rights formulated in accordance with a Eurocentric matrix.[4] As Linda Tuhiwai has argued, there is

(1) a legal framework inherited … which includes views about what constitutes admissible evidence and valid research; (2) a "textual" orientation, which will privilege the written text (seen as expert and research-based) over oral testimonies (a concession to Indigenous "elders"); (3) views about science, which will allow for the efficient selection and arrangement of "facts"; (4) "rules of practice" such as "values" and "morals," which all parties to the process are assumed to know and to have given their "consent" to abide by, for example, notions of "goodwill" and "truth telling"; (5) ideas about subjectivity and objectivity which have already determined the constitution of the tribunal and its "neutral" legal framework, but which will continue to frame the way the case is heard; (6) ideas about time and space, views related to history, what constitutes the appropriate length of a hearing, "shape" of a claim, size of the panel; (7) views about human nature, individual accountability and culpability; (8) the selection of speakers and experts, who speaks for whom, whose knowledge is presumed to be the "best fit" in relation to a set of proven "facts"; and (9) the politics … and the way those politics are managed by politicians and other agencies such as the media.[5]

Despite the fact that the right to culturally appropriate care is clearly established in General Comment 14 of the United Nations Committee on Economic, Social and Cultural Rights, legal and epistemological systems are overwhelmingly Eurocentric.[6] There are at least three key aspects of this reality that deserve further attention. First, the two primary references that can be used to address the problem of the right to health care from a legal perspective (biomedical law and the right to health care for Indigenous peoples) fall under the umbrella of a legal monism that assumes that the state is the only entity that produces and applies legal standards.[7] However, Indigenous peoples have their own systems of representation, values, and principles for regulating social organization that do not align with European approaches, and these must be considered legal systems in their own right (articles 5, 34, and 40 of the United Nations Declaration on the Rights of Indigenous Peoples). In the area of the right to health, this opens up the possibility of exploring the right to health care from an Indigenous perspective and of using an intercultural approach to the law.

Second, from an Indigenous perspective, producing evidence may require making assumptions

that are not shared by modern Eurocentric science. Science is based on naturalist assumptions; that is, it assumes the existence of an area of reality (nature) that is governed by its own laws (the laws of nature) and is separate from the domains in which intentionality, human action, agency, or historicity operate as a sphere of human decisions.[8] However, for the Aymara people, there is reciprocity between human and non-human entities (e.g., the *mallkus*, or sacred mountains) that departs from and surpasses naturalism.[9] Eurocentric science has been used to persecute, destroy, and colonize other forms of knowledge.[10] This leads us to ask how we can legitimize evidence that does not share the naturalistic assumptions of modern Eurocentric science. This is a problem of epistemic (and ontological) pluralism.[11]

Third, in the health care field, Indigenous peoples do not engage in medical monism. Rather, they articulate medical knowledge through praxis (especially biomedical and Indigenous medical knowledge). Should we restrict the analysis of the violation of rights to the evidence presented from a biomedical perspective? Do other forms of medical knowledge have the right to produce their own evidence, even if it does not coincide with the biomedical point of view? Through these questions, we show the problems that arise when using a homogenizing approach to medical pluralism.[12]

It was due to this complexity that we adopted the Indigenous research paradigm, which emerged in the 1970s and has since contributed to redefining research with and from Indigenous peoples. We use the term "Indigenous research paradigm" in the singular because this is how it is established in the literature.[13] Furthermore, it is important to note that this convention does not annul the diversity of Indigenous views; rather, it emphasizes shared aspects that go beyond and prevail over the colonial nature of scientific research. It is also clear to us that these views are specific to each Indigenous peoples and that differences exist between communities.

This complex approach is based on the need to decolonize research. The Indigenous research paradigm seeks to open up a space for including Indigenous people as producers of knowledge. This

stands in contrast to other research paradigms in which Indigenous peoples are seen only as objects.

Like any paradigm, it makes explicit the ontological, epistemological, and methodological assumptions implicit in conducting research.[14] The Indigenous research paradigm is unique in that it recognizes the participation of Indigenous peoples and considers their ontologies, methodologies, values, and sociocultural, economic, and political practices, most of which are symbolically or materially violated within the colonial logic of research.

This paradigm is the only one that allows us to work systematically from an ontological, epistemological, methodological, and axiological pluralistic perspective.

Specifically, it allows us to do the following:

1. Develop knowledge about Indigenous peoples that recognizes the connection between knowledge production and coloniality.

2. Recognize Indigenous peoples not only as objects of research but also as producers of knowledge.

3. Validate the intrinsic value of our *own* (Indigenous) knowledge, even when it does not fit into the scientific and naturalistic standpoint.

4. Adapt methodology to community practices, to their ethical standards and, at the same time, to the demands of academia.

5. Avoid separating knowledge production and the Indigenous political struggle.

6. De-center the focus on the individual and expand research to consider family, community, and territorial domains.[15]

Although there is a considerable amount of literature on health and Indigenous peoples, including studies on the right to health care as one of the fundamental aspects of the right to health, very little research has been conducted on the right to health care from the perspective of this paradigm.[16]

We have adopted the decolonization of methodologies perspective, which is very much a part of the Indigenous research paradigm.[17] In this paper, we develop the methodological proposal ad-

vanced by Adimelia Moscoso, which incorporates Aymara methodological practices.[18] Moscoso is a member of the Cancosa and Chalvire Indigenous communities. Over the course of her career, she has sought out research approaches that reduce the reproduction of colonial power and adapt to communities' characteristics and needs. In her master's degree thesis, she defined the categories required to do so: care through attachment, recognition of the Aymara approach to time and space, *lurjipan uñasiña* (observation), the use of oral archives, the use of broad thematic guidelines in the territory (*in situ*) of the Aymara, oral informed consent and reciprocity, responsibility, and respect for communities and individuals. She has determined that these safeguards are necessary for generating trust, security, and respect.[19]

We, the authors of this paper, are members of the Cooperativa Apacheta (Apacheta Cooperative), an entity focused on the rights of Indigenous peoples. The cooperative includes both Indigenous and non-Indigenous individuals. Our analyses reflect an interdisciplinary approach that draws on expertise developed in the fields of medical anthropology, sociology, psychology, Indigenous rights, and the right to health. Most importantly, they reflect our scientifically informed Indigenous perspective, which has been forged through intercultural dialogue involving members of Aymara communities in the Tarapacá region and non-Indigenous stakeholders who have been supporting Aymara struggles for more than a decade.[20] As a result, each time we identify the analysis as emerging from our Indigenous perspective, the reader must recall that we are presenting analyses rooted mainly in local Aymara culture. While those analyses may be informed by the various scientific disciplines in which we have been trained, that training also allows us to identify aspects that are fundamental to the analysis that we are conducting but that the scientific approach leaves out.

We note that most of the analyses that we conduct from our Indigenous perspective reflect the reality of Indigenous elders living in rural communities in the Tarapacá region. This reality differs from that of the Aymara who belong to other age groups or who live in other localities (especially urban spaces), and the forms they have adopted in terms of Indigenous cultural practices.

The paper is structured as follows: We begin by presenting the main aspects of Doña Francisca's case. We then analyze them from the perspective of the Indigenous research paradigm. This means that we include arguments grounded in scientific disciplines, as well as arguments that arise from our own Indigenous perspective. Finally, we outline the main conclusions that can be reached based on this case to elucidate critical aspects of the Indigenous research paradigm in the analysis of the right to health of Indigenous peoples.

The case of Doña Francisca

Doña Francisca came from a family of farmers and artisans that is part of the Willq'e community. Its members follow a centuries-old tradition based on Andean medical knowledge.[21] The medicine practiced by the people of this community is not a form of "alternative" medicine; rather, it is their primary form of health care, and they prefer it over biomedicine due to the undesired side effects of the latter. Doña Francisca was recognized as a wise woman, as she was one of the few people alive familiar with her culture's knowledge. In this respect, she took on the responsibility of conveying this knowledge to the new generations. This is one of the main objectives of the Children of Willq'e Aymara Indigenous Association, of which she was a founding member.

Doña Francisca eventually sought care at the family health center in the village of Pica, a state-run clinic based on a biomedical approach. Her chief complaints were type 2 diabetes (for which she received insulin), high blood pressure, and stage 5 chronic kidney failure (which was under control). However, in July 2019, she stopped going to the center because her medications began to produce side effects. The doctors told her she needed to use a catheter, but Francisca refused to consent to that approach. Francisca also told her family that she did not want to undergo dialysis.

Doña Francisca was also being treated in accordance with Andean medical knowledge with

the help of her partner, Francisco, a traditional *yat-iri* (Andean shaman) and *qulliri* (bone-setter and herbalist) from the village of Caquena in Putre. According to her family and Francisco, the treatment was based on plants such as *pingo pingo*, quinoa bark, *marancela*, parsley, and celery. Francisca also received care at home, which helped her on various occasions when she was seriously ill.

On Friday, August 28, 2020, an ambulance arrived at Francisca's home. No one had called for it. It is still not clear why it was sent. Maybe a neighbor was worried; maybe the health center took the initiative. Whatever the case, the ambulance crew took Francisca with them, telling her that she was only to undergo tests at the health center, which was untrue. She and her partner voiced their opposition, but they took her with the excuse that they needed to extract liquid from her lungs and would bring her back home promptly. They said they would call her sons to update them. They administered a PCR test for COVID-19 and proceeded to take her to the city of Iquique (more than 117 kilometers away). All of this was done without consulting with or informing her family. Francisco told his partner's son what was happening. With the help of an acquaintance who worked in the hospital in Iquique, the son found out that his mother was in a special ward for people suspected of having COVID-19. The doctor on duty told him that his mother was stable and that they had decided to keep her in the ward until Monday.

On Monday, August 31, the PCR test results became available and indicated that Francisca had COVID-19. The entire family was ordered to quarantine in their home, even though her son regularly took PCR tests for work. The son asked to take another PCR but was forcefully told that he could not. The family was told they would be fined if they did not comply with the quarantine. Their inability to be with and support Francisca had a significant emotional impact on the family.

The next day, Tuesday, September 1, arrangements were made to bring Francisca home so that she could continue to quarantine there. She was released from the hospital on Wednesday, September 2. However, she was in an awful physical and mental condition; she could not recognize anyone or even speak. No one in the house slept that night because of her pain and discomfort.

On Thursday, September 3, a doctor was called to examine Francisca and decided that she would have to return to the hospital in Iquique. She was taken back to the facility that same day. The family received a call from the hospital that evening informing them that she was seriously ill and was not likely to survive. The family was told that Francisca had passed away the next day at approximately 2 a.m.

Because her son and her partner were in quarantine, one of Francisca's sisters had to manage the matters related to her death. The sister asked the funeral home to drive the hearse past her house so that Francisca's son and her partner could say some semblance of a goodbye. However, the health officials and the police refused to allow this. As a result, the family had to wait for their quarantine to end and for the cemeteries to reopen to say their farewells, which did not occur until the end of October. The family is still dismayed by what happened so abruptly to Francisca, as they feel it was not her time. Some of them are receiving psychological support because of the circumstances surrounding her death, which have made it very difficult for them to mourn.

All of this was included in a complaint alleging that Francisca's rights had been violated because the facility failed to provide culturally appropriate care, ask for informed consent, and respect patient and family decisions. Such rights are guaranteed by Chilean Law 20584 on Patients' Rights and Duties, which also outlines a procedure for filing complaints so facilities can remedy irregularities. The aforementioned regulation also allows for an appeal to be filed with the Health Superintendency if the response to the claim is unsatisfactory or the irregularities reported are not addressed.

Once the complaint was filed, the family health center issued a written response concluding "that there was no lack of service as alleged by the claimant, nor a violation of the patient's rights, mainly because the medical care provided was within our powers as a primary care provider."

This response was deemed unsatisfactory

by the family, who took the case to the Health Superintendency, where it is currently pending. The following analysis addresses Doña Francisca's experience and elements of the written response provided by the family health center. Both elements are part of the same alleged lack of cultural appropriateness.

The violation of the right to health from the perspective of the Indigenous research paradigm

The events described above constitute clear violations of the right to health. Certain elements would constitute a violation of any person's rights. The most prominent are the provision of incomplete information, insisting on performing procedures without the patient's consent, and the exposure to risks associated with the care received when a precise diagnosis has not been provided. Furthermore, other interventions specifically violated the right to health care of Indigenous peoples, including the obligation to protect free and equal access to health care promotion, protection, and recovery, as well as an adequate response to the other factors that influence health, as enshrined in international law (including Convention 169 of the International Labour Organization; the United Nations Declaration on the Rights of Indigenous Peoples; the American Convention on Human Rights; the Universal Declaration of Human Rights; and the International Covenant on Economic, Social and Cultural Rights).[22] We examine this in greater detail in the paragraphs that follow.

Failure to provide culturally appropriate health care

The health system recognized the absence of culturally appropriate care but tried to hold Francisca responsible for this deficiency. The institutional written argument was that "when the patient's medical file was reviewed … it was impossible to find any request of culturally appropriate attention."[23] This deficit is a clear violation of international standards on the right to health of Indigenous peoples. As noted in an interpretative guide to Convention

169 of the International Labour Organization, "Right to basic health care is a fundamental right to life and States have an obligation to provide proper health services to all citizens."[24]

According to Chilean regulations—Indigenous Peoples Health Policy, General Norm 16 on "interculturality in health services"—culturally appropriate attention does not depend on a request made by the patient. It is actually the health care provider's responsibility.[25] Comprehensive services with an intercultural approach must be made available to guarantee access to health care. As stated in the policy, "The model of care with an intercultural approach must incorporate cultural appropriateness of services, understood as the adaptation of services to the characteristics of the culture."[26] This means that it is not enough to develop such programs. As noted by Jorge Contesse, there must also be "training for health care operators in conducting case-by-case analyses of ethnic affiliation and the possible implications that said circumstance would have for the provision of an examination and treatment."[27] This is even more critical in cases in which providers are aware that the patient identifies as a member of an Indigenous community, as in this case.

Furthermore, health care personnel cannot assume that the patient knows how to request culturally appropriate health care. It is thus essential to identify cultural affiliations and take special measures regarding members of Indigenous communities. The application of the principle of equality and nondiscrimination in access to human rights does not mean that the same treatment should be given to all people.[28] On the contrary, much attention has been paid to taking special steps to eliminate any determinants that lead to discrimination.

From our Indigenous perspective, this kind of adaptation to the health system is the minimum needed considering the history of colonial and state violence against Indigenous communities and their medical knowledge.

Lack of familiarity with the articulation of medical knowledge

One of the arguments in the state's written response

to the complaint is that culturally appropriate health care was not only not requested but unnecessary. The response states, "In fact, she has been visiting our family health center for various treatments and benefits for years." [29] Regarding this point, we must first clarify that an Indigenous person seeking care at a biomedical health care center, even over a prolonged period, does not exempt the center from its duty to provide culturally appropriate health care. On the contrary, it is precisely the fact that native peoples use biomedical treatment and Indigenous medical practices simultaneously that makes such a provision imperative. Medical anthropology has studied this for more than 50 years in terms of medical pluralism, stressing that in the case of Indigenous peoples, there is often an articulation between different forms of medical knowledge and not the exclusive use of one or the other.[30] The same point has been raised in the Tarapacá region of Chile.[31]

Which aspects can facilitate or hinder such articulation from our Indigenous point of view? First, if an ailment occurs within the family domain and is handled by an Indigenous health care provider, it is unlikely that the ailing person will visit a biomedical health center. Biomedical care is imperative only in certain situations—for example, when it is deemed that a person is close to death and that such attention can prolong their existence in the earthly domain (*Aka Pacha*).

Second, the reluctance among Aymara elders to rely on care provided by the family center is often due to the proposed interventions being considered invasive, from a perspective in which the body must be kept "closed" to protect a person's health; thus, any interventions that "open up the body" are rejected.[32]

Third, such reluctance is related to the side effects of conventional medicines. For the Indigenous communities of the Tarapacá region, it is believed that patented medications may benefit one part of the body but harm another. This is based on a relational understanding of the human body. Members of these communities believe that treatment based on medicinal plants always benefits the entire organism and has no side effects.[33] In this regard,

protocols for providing treatments with cultural appropriateness do not exist within the Chilean biomedical system. From our Indigenous perspective, special consideration is necessary, especially in the case of the elderly, as they are accustomed to treatments based on medicinal herbs and understand that their bodies have less resistance to the ingestion of chemical elements.

Fourth, the willingness to seek treatment will depend significantly on *recibimiento* (reception), the way trust and familiarity are forged. "Reception" allows people to express how they are experiencing the ailment emotionally, physically, and spiritually. If there is no respectful approach, especially with a *jachamama* (grandmother), there is unlikely to be a willingness to reveal their actual ailments. These ailments may be related to their failure to deliver on promises made to protective entities such as *Alak Pacha*, *Manqha Pacha*, and the saints. The intercultural facilitator, a state employee belonging to an Indigenous people whose role is to articulate the needs of users of Indigenous origin with the health care network, should play a vital role in this context because they must understand the patient's language and worldview. They must also pay attention to the history of persecution and subordination of the patient's forms of knowledge. This is critical because even today, health care teams hold prejudices, disparage patients' beliefs, and punish patients who ascribe to other world views.[34]

From our Indigenous point of view, the criticism of Doña Francisca's decision to visit the family health center "only intermittently" (as the written response describes) is grounded in medical monism. By insistently denying the contribution made by Indigenous medical knowledge to the treatment of Francisca's ailments, the health center interprets the *alternating* between both forms of medical knowledge as an interruption of treatment (*intermittency*). In other words, a situation of medical pluralism is *negatively* perceived from a monistic medical perspective.

This monism is in and of itself a violation of rights, given that Chile's health care policy on Indigenous people states that "the recognition that no medical system can satisfy all health care

needs on its own suggests that the official model should not be viewed as the only desirable and valid approach."[35]

The imposition of biomedical interventions without the patient's consent

An additional element of the lack of cultural appropriateness was the failure to secure free and informed consent to the proposed biomedical treatment. The complaint established that Francisca was misled about the medical procedures, where she would be taken, and how long she would be away from home. This information was provided without the assistance of an intercultural facilitator, although Chilean regulations require such services to be provided.

According to these regulations, "Intercultural facilitators should be the link between the health team and the indigenous communities. They must be people who belong to an indigenous community and be endorsed by it." Among their functions, the regulations note, are to "guide, inform and support the patient and their family members when they require outpatient and inpatient health care [and] … support the patient and the health team in resolving situations where the cultural aspect is relevant to health recovery."[36]

In Francisca's case, the entire informed consent procedure was flawed because it entailed coercion.[37] This coercion occurred when she was at home with her partner, and the ambulance came to take her away. Considering that she was refusing the medical care, the medical personnel needed a written and signed document proving that refusal. However, Doña Francisca was afraid of signing any document in light of other occasions in which such a signature brought adverse consequences to her and her community. She also observed that the staff was especially insistent on having her sign, which further entrenched her distrust of the situation. Later, we will discuss historical-structural reasons for her refusal to sign.

The critical point here is that when the complaint points out that Doña Francisca was taken against her will, the health center's response asserts that the lack of a signed document refusing the treatment proves a *tacit* expression of willingness on her part. This assertion misinterprets the facts because the lack of such a signed document reflects her refusal to sign and is not a "tacit expression of willingness" on her part.

From our Indigenous perspective, we are fully aware of the negative impacts that the signing of documents has had on our people.[38] This historical reality underpins Francisca's mistrust and should lead us to consider that it is legitimate for a person's consent to be expressed orally and in their mother tongue. Historically, the Aymara people have used the spoken word to transmit, communicate, dialogue, and legitimize their present and past experiences. From the Indigenous perspective, oral expression has as much or more value than the written word because it has an axiological meaning: it brings the *value of the word* into play.[39]

Such a refusal should have led to the search for all possible alternatives to provide culturally appropriate information. The staff's failure to do so calls into question the procedure of consent. How can someone validly give their consent to something if they do not fully understand what it is they agree to? The violation of this point is critical, even from the point of view of hegemonic law. As Valentina Fajreldin puts it, "as this relationship [doctor-patient] also involves an asymmetry of power, the international debate has focused on the model of autonomy, which as a general principle posits the defense of individual freedoms, such as the right of patients to make decisions about their bodies concerning medical treatment that is often technocratic and dehumanized."[40]

From our Indigenous perspective, a critique can be formulated regarding the naturalization of protocol-based interventions, which are understood from a universal perspective that assumes they are good for everyone and thus unquestionable. However, the claim of universality is a form of cultural monism, embedded in biomedicine, which contradicts the Indigenous approach to health care. Interventions can be harmful, yet from the biomedical perspective, they are rarely considered as such because they have been conceived with the explicit purpose of being beneficial. It is thus fundamental

to consider the Indigenous perspective in order to identify any harm not perceived from a biomedical perspective.

More importantly, contextual conditions that allow the expression of willingness without constraints or coercion should be safeguarded. From our Indigenous point of view, this supposes a context of respect, responsibility, and reciprocity. As Linda Tuhiwai Smith points out, consent is relative, as there is no specific period for the generation of said trust with the *jachamamas* (grandmothers) and *jachatatas* (grandfathers). It can take minutes, months, or even years, as this is granted depending on the credibility of the person requesting it.[41] Furthermore, any trust granted is assumed to be reciprocal, taking place within a negotiation context, and is not a static decision. Therefore, the quality of the interaction is much more important than the signing of a document. Signing a document thus becomes more of a barrier than an avenue to dialogue and understanding, which is why incorporating oral informed consent in research has been highlighted.[42]

The exclusion of the qulliri

The state's written response to the complaint had a double impact on the family. In addition to the harm they suffered, there was now a direct attempt to delegitimize the character and medical knowledge of one of its members, Francisco. Even if he was not present during the sequence of actions we have described, the intercultural facilitator of the family health center engaged in this delegitimation using the following argument in the written response: "One becomes a *qulliri* or *yatiri* through the recognition granted by the local Indigenous community. Francisco *is not recognized as such in Pica*."[43]

On the contrary, his local community recognized Francisco as a *qulliri* and *yatiri*, as established in the minutes of Meeting 16 (March 2, 2021) of the Children of Willq'e Aymara Indigenous Association.[44] Furthermore, according to an interview conducted by our cooperative with Francisco on June 12, 2021, he has performed this role for 60 years and has done so consistently during the 30 years he has lived in Pica.

It is thus clear that any denial of this status represents an act of symbolic violence in the context of intercultural health. Symbolic violence is "a form of violence exercised without physical coercion through the different symbolic forms that make up people's minds and give meaning to action."[45] Given that, from the Indigenous point of view, medical knowledge is connected to other areas of life, delegitimizing their health knowledge also calls into question their knowledge regarding other cultural and social dimensions, such as ceremonies, rituals, music, singing, weaving, and their native language.[46]

Within our Indigenous perspective, this delegitimization is clearly related to communities' oral histories. This kind of action has constituted the foundation for historical processes of genocide that began with European colonization (extirpation of idolatries) and then transformed into assimilation processes. The most worrying aspect is that such delegitimization is enacted by an agent of the state, which monopolizes legitimation and delegitimation in Western society. Thus, this represents a moral affront and one more act of "epistemicide" (the killing of knowledge systems).[47]

This delegitimation contradicts the spirit of Chile's Indigenous Peoples Health Policy, which, at least nominally, recognizes Indigenous medical knowledge:

> there is an urgent need to accept that native peoples have different concepts of health and disease and that there are traditional specialists for diseases that the official health system will never know how to cure, as it lacks the codes to understand their etiology, and therefore their rehabilitation, much less their prevention.[48]

For this reason, Administrative General Norm 16, concerning interculturality in health services, establishes that "the Ministry of Health, health services, and other health sector bodies will ensure their actions guarantee the respect, recognition, and protection of the health systems of indigenous groups and their traditional agents recognized within their communities."[49]

The state enjoys symbolic power that is reinforced by a legal structure. Therefore, the fact that a state agent engages in this type of disqualification represents a form of unacceptable symbolic violence. From our Indigenous perspective, it also contravenes community values in that a person belonging to the community must respect their elders. This respect is based on recognizing the accumulated knowledge and contribution to the community's care and development. It is important to note that Francisco's contribution as a *yatiri* involves human and non-human members of his community and territory.

The delegitimization of Andean medical knowledge

Moreover, it is equally unacceptable for the intercultural facilitator to serve as the spokesperson for a point of view that calls into question the effectiveness of Andean medical knowledge. The state's response to the complaint indicates that the intercultural facilitator

> *pointed out that, unfortunately, indigenous medicine did not evolve due to the impact of colonization, technology, globalization, etc. The person in question acknowledged that indigenous medicine, particularly that of the Aymara, is good. However, such knowledge is limited to preventive or palliative treatment, but there is no possibility that a person with chronic ailments such as those suffered by Francisca could have been stabilized or treated only with natural medicine.*[50]

In this regard, it is necessary to clarify that from the point of view of medical anthropology, there is no basis for suggesting that Indigenous medicine has not evolved. Critical medical anthropology has defined medical knowledge as a process of transformation in a permanent state of flux that adjusts to the health needs of communities and territories.[51] Moreover, considering that medical knowledge is not isolated, the scientific literature on medical pluralism has consistently described the multiple transformations that have occurred in the medical knowledge of native peoples, mainly due to the connection with biomedical knowledge, which has often consisted of the incorporation of different

preventive, diagnostic, or therapeutic elements. Furthermore, recent research on this issue shows that the processes of cross-border mobility connect the transformation of Andean medical knowledge in northern Chile to changes happening in neighboring countries (Bolivia and Peru).[52] The passage of a law on traditional ancestral medicine in Bolivia in 2013 has reinvigorated that process.

Viewed from our Indigenous perspective, it is important to note that the defense of cultural integrity does not necessarily mean maintaining forms of existence that are tied to the past. One of the inherent characteristics of a cosmovision is the establishment of certain principles that link life to different planes, some of the most important of which are the symbolic, social, cultural, political, spiritual, and territorial. However, these principles are not restricted to the past; there is a reciprocal transformation of the cosmovision based on reality and of reality based on the cosmovision.

Moreover, contemporary discussion in the field of medical anthropology on the effectiveness of Indigenous medical knowledge highlights that its complexity requires an approach that goes beyond traditional Eurocentric scientific knowledge.[53] The facilitator's value judgment only reproduces the prejudices present within the ideology of biomedicine, which subordinates Indigenous medical knowledge in assuming that it is palliative (non-curative), ineffective, or iatrogenic. In the international literature, such judgments have been exposed as part of the "hidden values" that operate as "tenacious assumptions of biomedicine," one of which is the assumption of the inefficiency of non-scientific knowledge.[54] Medical anthropology literature has documented and analyzed this in detail, including the specific case of the Tarapacá region of Chile.[55] Consequently, the question of whether "a person with chronic ailments such as those suffered by Francisca could have been stabilized or treated only with natural medicine" is a matter that involves seeking out and presenting evidence. Further, there is no evidence of this assertion in the written response.

Given all of this, the judgments issued by the intercultural facilitator seemed to reflect his

"internal colonialism."[56] Scholarship in the social sciences has found the role that some Indigenous people play within the structure of the neoliberal multicultural state to be problematic. Scholars have denounced the figure of the "authorized Indian" (*Indio permitido*): "that person who assumes an ornamental role in the new state" and who, in the political sphere, "speaks in modern terms, translating their practices into a politically acceptable discourse and leaving the unacceptable outside of the public domain, without necessarily abandoning them."[57] From our Indigenous perspective, this also constitutes an attack on the culture from within, which in the Andean axiology implies a lack of loyalty, a betrayal of the community, and an affront to a person's own cultural identity.

Lastly, using the authority conferred on the intercultural facilitator to discredit Andean medical knowledge is arbitrary, as the facilitator does not receive any form of legitimacy from the anthropological sciences, biomedical knowledge, or community recognition. As a result, the official's judgment subverts the roles assigned within Chilean institutional and intercultural health care.

The deterioration of the relationship between biomedical and Indigenous knowledge

We have identified a need to move away from analysis at the individual level and focus on the territory, the community, and the family. This approach is very much part of our Indigenous perspective. Events like those analyzed in this paper cause harm not only to an individual's health but also to the collective health of the Aymara people, as they represent the reproduction of biomedical dominance over Indigenous medical knowledge. Indigenous medical knowledge is identified by academics and political bodies (see the Historical Truth and the New Deal with Indigenous Peoples Commission) as one of the pillars of cultural identity.[58] If this type of rights violation is repeated, medical knowledge with territorial specificity cultivated and protected by people like Francisco is made to disappear. Indeed, the refusal of the health service to recognize the knowledge of people like him is part of the symbolic violence that forms the basis of the difficulties

of passing this knowledge on to new generations. Thus, collective and transgenerational harm is caused that should be avoided from an intercultural point of view.

Conclusion

States must be more willing to develop efficient structures and public policies that guarantee respect for the human rights of Indigenous peoples. Political officials must take responsibility for promoting these rights beyond the formalities that have been used for so many years to prevent them from being exercised. Despite abundant national and international regulations on the subject, the right to cultural appropriateness in health care has not permeated the institutional and cultural structure of the health system in Chile, and minimal progress has been made.

According to the Indigenous research paradigm, intercultural health is yet another sphere in which the coloniality of knowledge and power continues to operate. The need to sustain an Indigenous paradigm is based on the fact that many of the aspects identified as problematic are neither perceptible nor acquire the character of validated evidence.

The problem of evidence comes to the fore in the domains of scientific knowledge and in the law, specifically regarding the right to health. First, knowledge validation procedures are culturally determined. Second, the Indigenous perspective must be fully included in interpreting what constitutes a violation of rights. Fully included means including ontology, epistemology, methodology, and axiology in order to refrain from reproducing certain tenacious biomedical assumptions. We have offered various examples throughout this paper: the idea that the only truth is the naturalist one, that non-biomedical knowledge is inferior, that biomedical knowledge guarantees universal well-being, that the ideal approach to health care is medical monism, that Indigenous knowledge is opposed to its scientific counterpart, and that the only valid reference for assessing the right to health care is the Eurocentric model of law.

Throughout this paper, we have argued that the right to health care can benefit from the Indigenous research paradigm. Moreover, the contributions of this paradigm are not limited to the approach to Indigenous issues; they can be extended to all aspects in which a stakeholder's point of view becomes relevant in ontological, epistemological, methodological, and axiological terms.

Acknowledgments

Ethics approval

This study was conducted in accordance with the Helsinki Declaration and was approved by the Universidad de Tarapacá Scientific Ethics Committee for studies involving humans (reference number 27/2020). We obtained informed consent from all of the subjects involved in the study.

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The Commoditization of Ecosystems within Chile's Mapuche Territory: A Violation of the Human Right to Health

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Abstract

The Araucanía region of Chile is characterized by a significant rural Indigenous population—the Mapuche people—who preserve their cultural beliefs about the world around them. This region is also distinguished by the conflict between the Mapuche people and the Chilean government. The Chilean state has supported the development of extractive projects such as industrial plantations, hydroelectric plants, and aquaculture, using nature to generate profits. This has collided with the Mapuche's inextricable relationship with nature and territory, which they value as a spiritual and historical space. Our qualitative study, conducted between 2016 and 2019 in three Araucanía territories with large Mapuche populations, sought to explore Mapuche perceptions of nature, their right to health, Indigenous rights generally, and Indigenous communities' relationship with the state. The results show an overall perception among Mapuche communities of an extractive mentality at the heart of the Chilean state, regardless of the administration in power, as well as a belief that the industrial occupation of their territories represents a process of colonialism and the transgression of ancestral rights. This extractivist approach by the state has caused Mapuche communities to witness enormous changes to their ecosystem, with negative impacts on their well-being.

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Introduction

In 1948, the World Health Organization, an organ of the United Nations, declared health a fundamental human right.[1] Subsequent international treaties, declarations, conventions, and general norms have incorporated specific health guarantees for Indigenous and tribal peoples. Among them is Convention 169 of the International Labour Organization, which recognizes the Indigenous therapeutic practices of prevention and healing, along with the collective and territorial rights of Indigenous peoples, and demands that states adopt special measures for the protection and development of such practices.[2] In 2009, Chile ratified this convention and, in doing so, legally recognized the existence of nine Indigenous peoples and their particular notion of territory and cosmovision. This acknowledgment was strengthened by the international agreement known as the Indigenous Peoples' Health Initiative, which emphasizes the need to adopt a holistic approach to Indigenous health treatment, including the need to adopt an integral and intercultural health perspective.[3]

These international agreements concerning Indigenous peoples and health are further complemented by the United Nations Declaration on the Rights of Indigenous Peoples.[4] This declaration protects Indigenous peoples' rights to conserve and strengthen their institutions; to physical and mental integrity; not to be subjected to forced assimilation; not to be displaced from their native lands or territories; to preserve their spiritual relationship with the ecosystem; to protect their traditional medicines and health practices; and to live in a healthy environment. The declaration further notes that states should recognize Indigenous ecosystems and provide resources for the reparation, restitution, and legal protection of Indigenous territories.

The Economic Commission for Latin America and the Caribbean stipulates that states must guarantee the self-determination of Indigenous peoples over their ancestral lands, territories, and natural resources because they represent the fundamental bases for Indigenous well-being.[5]

In 1993, Chile passed Law 19253, which establishes norms for protecting and developing the life of native peoples residing in the country. The purpose of this law is to protect the cultural and health patrimony of Indigenous peoples. Furthermore, the law regulates the participation of Indigenous peoples in decisions regarding development projects that stand to affect them. In 2008, the government created the Historic Truth and New Deal Commission and rolled out new policies on the relationship between the state and Indigenous peoples.[6] In this context, an Indigenous health policy was created, along with certain regulations to implement it. The regulations concern the rights and duties of health users and establish that in territories whose populations consist of more than 20% Indigenous people, the Chilean state must guarantee intercultural initiatives.[7] As a result, the health rights of Indigenous people became associated with the concepts of the ecosystem and territory. Different authors have studied this issue, analyzing development, identity, health, and territory as rights of Indigenous peoples.[8] Despite this progress in public policies, there are still critical structural gaps in recognizing the relationship between the natural environment and Indigenous peoples' well-being and healing.[9]

In Chile, conflicts have arisen concerning the Mapuche people, the country's largest Indigenous group, particularly their claims to autonomy over their historical territories, which are currently being exploited by private and transnational companies for commercial purposes.[10]

Despite progress in regulations at the national level, the Chilean state exerts minimal oversight over the extractive activities of timber companies, and it does not recognize the inextricable relationship between Indigenous people, territory, and health.[11] The Mapuche, whose claims to territorial rights have been criminalized, have also experienced judicial persecution for struggling against extractive capitalism.[12] Consequently, the concern for ensuring the population's health from a perspective of law and interculturality has become subsumed into issues of territorial conflict.

For the Mapuche, territory has philosophical and cultural significance and represents more than a piece of land. It embodies a symbolic category that articulates the history of their ancestors,

nature, health, and reproduction and is therefore considered sacred.[13] Likewise, health is understood as the relationship between human beings, nature, and ancestors.

Chile's extractive approach to nature, inherent to positivist thinking, collides with the cosmovision of the Mapuche and has been a source of constant conflict between the state and this Indigenous group.[14] A vast area of the once pristine Mapuche territory has been exploited by the forestry (pulp and paper) industry. Although some Mapuche communities have benefited from forestry in terms of employment and income, most are against the advance of forestry.[15]

Regardless of the Chilean state's efforts to incorporate international standards concerning ancestral peoples, such attempts have been insufficient and limited.[16] The positivist logic, which underpins the current Chilean Constitution, conceives of ecosystems as unlimited resources that can be exploited, while reducing the concept of health to an individual right associated with curative biomedical benefits.[17] These principles contradict the Mapuche epistemology that links health to the natural ecosystem and promotes nature's protection and recognition as a subject of rights, which is thus opposed to the capitalist concept of commodities.[18]

Few empirical studies on Indigenous populations in Chile have involved a combined analysis on culture, ancestral territorial rights, and collective well-being.[19] We analyze these changes and gaps in relation to health and rights from the framework of Collective Health in Latin America with special attention to Indigenous knowledge and experience in Chile.[20] This paper presents qualitative research on the perceptions of Mapuche people living in the Araucanía region about their ecosystem, health, and relationship with the Chilean state. It provides insights into how the Mapuche live and feel regarding the fulfillment of their Indigenous rights to land and health.

Methodology

We undertook a descriptive and qualitative study from 2016 to 2019 in La Araucanía, Chile, located 686 kilometers south of Santiago, the country's capital. This region is inhabited by the largest Indigenous community in Chile—the Mapuche—who make up 9.9% of the national population.[21] In La Araucanía, 32.8% of the population belongs to the Mapuche people; and of these, 70% live in rural areas.[22]

These rural Mapuche inhabitants live in small family communities far from urban areas; they are principally farmers who raise livestock and cultivate vegetables, and in some areas, they rely on handiwork as a means of subsistence. Many of these rural communities are surrounded by timber companies that have established forest monocultures and a network of roads designed for industrial plantations. Given the current unrest in these territories, most companies employ armed security guards to protect their extractive activities.

Thirty adults who self-identified as Mapuche, belonging to three ecological-cultural zones in the Araucanía region, participated in our study. The ecological-cultural zones are described as the coast (*lafkenche*), center or intermediate depression (*wenteche*), and mountain range (*pewenche*).[23]

The participants consisted of 21 men and 9 women, with an average age of 39 years and an average of seven years of formal education; 28 people were married with children, and 25 respondents participated in land rights organizations.

We coordinated data collection with Mapuche cultural advisors (local Indigenous people), who facilitated our work with participants and accompanied us in the data collection process.

Data was collected through focus groups and interviews conducted in the communities. We obtained participants' informed consent prior to data collection. This study was authorized by the Scientific Ethics Committee of the Araucanía Health Service and Universidad de La Frontera.

The interviews and focus group conversations were transcribed and entered into a database in the Atlas.ti 10 program. We then segmented the stories into units of meaning; coded the text to compress information; grouped codes of similar meanings; designed a descriptive network or map to observe relationships among meanings; performed a nar-

rative interpretation of findings; and developed results and findings congruent with the discourses.

The reliability and rigor of our research process was ensured through data collection triangulation (i.e., groups and individuals) and the participation of various analysts in the process of determining results.

Results

Three themes emerged that reflect the Mapuche population's perception of the relationship between the ecosystem and their health rights. First, extractive policies have been encouraged and supported by the Chilean state. These policies are considered structural factors not modifiable in the short term. Second, ecosystemic changes have generated uncertainty and a lack of well-being in the population. These changes are perceived as a violation of the right to health. Third, state policies and regulations are considered forms of colonialism that violate Indigenous ancestral rights.

Extractive policies promoted by the Chilean state are independent of the administration in power

Interviewees consider that there is a lack of vision from the Chilean state concerning the importance of the Mapuche people in the country's history and development. Although various policies and laws regarding Indigenous peoples and institutions have been created to address global issues of Indigenous development, they are focused on compensating families for historical and recent economic damage. Several comments from participants illustrate this idea:

> The state believes it is doing a favor to the Mapuche people by helping them, but no, it is our right. We always had the same problem, the importance of our community as a people is unknown, and our history, organization, language, education, and medicine are ignored. (interviewee 2)

> In schools, students are taught that the Mapuche people are part of history; the Mapuche people are seen as having disappeared. That is not appreciating

> that they are a living population, a nation, not isolated people in each community. (interviewee 10)

> The policy has always been to corner us. They occupy our ancestral territory and hand it over to the companies that take everything, the native forest and the water, rendering everything useless. (interviewee 1)

In this context, the state has embraced a repeated policy of ignorance, which has become a structural factor threatening the life and developmental possibilities of the Mapuche people. For example:

> There have been advances, but always because the Mapuche fight for their rights and continue fighting. There is CONADI [National Corporation for Indigenous Development], laws, and regulations that Chileans make for us, that have lived here before the arrival of the Spaniards. (interviewee 7)

> They blame the Mapuche, and militarized our territories. This will not easily change until other laws reign ... our laws. The truth is that our existence as a Mapuche people-nation is ignored, and that ignorance is installed within Chilean society. (interviewee 10)

Changes affecting the ecosystem have generated uncertainty and a lack of well-being, which constitutes a violation of the right to health

As stated in the introduction, the Mapuche cosmovision and people are inextricably bound to the territory and nature. For them, nature is not only a physical environment but also a spiritual space of interconnection where Mapuche beings coexist with their ancestors. This relationship of reciprocity, while hierarchical, is supported through mutual respect that generates a balance between being and nature. This balance is expressed in the concept of well-being (health) for humans and non-humans, present and past. Consequently, every element that disturbs nature affects all beings that make up this system.

All the people interviewed mentioned the presence of significant changes in nature that have affected the health and well-being of the Mapuche people.

These changes are the result not only of human settlement but also of the interventions of monoculture forestry plantations and water extraction companies. Some excerpts exemplify this idea:

> If you enter a place and you ravage the spirituality of the space, there will be a shock, a disturbance from that encounter, and it will disrupt your spirituality. This disruption is the origin of the imbalance. As your spirituality and body are one, it will have repercussions, it will affect you, and you will see it later reflected in the body. (interviewee 1)

> The business enterprises come to take everything away from you, and you are left with nothing; they leave you hopeless, and for sure, that emotional part of you will trigger an illness. Your mind, your thoughts at night, being unable to sleep or eat because your mind cannot organize itself. If everything is taken away from you, you cannot properly nourish yourself and sleep well. In other words, it affects my body because I am a whole, do you understand? (interviewee 12)

> All Mapuche people come with a role in the community: to take care of our surroundings, to protect and take care of the land, to take care of nature, to be watchful of what is happening with the water sources, what is happening with the herbs, with the trees, the medicinal resources. It is a whole; to live, we have a whole set of elements. We cannot isolate ourselves and say: I can live alone without these elements. If these elements are missing, you have lost your life and who you are and are no longer human. You are already a machine, you are mechanized in the system. (interviewee 17)

A community leader told us:

> Everything is related to us, not only the issue of health but also the issue of roads, the issue of bridges, the issue of education, and different issues with the communities. All areas of development, especially in fundamental rights, health, education, and roads, mean having good accessibility to the city, right? Those are the rights of the communities. (interviewee 5)

Another said:

> The companies take everything away: that makes us sick, it does not allow us to prosper, it is like taking away the community's right to exist. (interviewee 10)

Some people stated that even Mapuche medicine and its agents had been affected by changes in nature:

> It is harder to go to look for remedies [medicinal herbs], the menoco [places with vegetation and water] are getting farther and farther away from where we used to live, because they have been depleted, and so our machi [traditional healers] suffer … they are becoming lost. Even to take plants from the mountain, we have to ask permission from the Chilean institutions. Can you see? We were the owners of that mountain. (interviewee 2)

> Nature has also changed over time, the air that surrounds us, it is not like before, before there were all the natives, there was the river, there were waterfalls, the mañines [swamps], the river carried much water to the sea, everything was abundant. Now, it no longer exists. So, the air is different; it is not like before. Before, when you spoke, it echoed; now you speak, you speak again, and there is no echo. (interviewee 2)

There is a perception of colonialism and a transgression of Mapuche ancestral rights

The Mapuche people share a spiritual and cultural history related to the creation of the universe, people, and nature. As a nation, they are a civilization previous to the Spanish conquest, but one brought down by war and occupation and then forced to abandon their ancestral territories, thus transforming their political, economic, and social organization.

Many interviewees described this colonization and neocolonization as a severe loss and a trauma in their people's history. However, at the same time, they expressed their spirit of struggle to recover and validate their constitutional rights:

> Colonialism is an issue if one follows history, starting with the defeat of the Mapuche people by the Chilean army when the fundamental rights of the Mapuche people were not respected. When the Chilean army in 1879 to 1880 came and overran the Mapuche people with weapons, they annihilated and won the war; they burned their houses, took their animals, and impoverished them in such a way. Then a problem started because they killed their families, and they cornered them. (interviewee 15)

Another participant pointed out that the Mapuche people's right to have their own organization has been transgressed. In their words:

> How we are led, directed, and structured as a people or nation is different from the other customs. Today the longko [Mapuche political authority] is compared to the president of a community or an organization. The westerners brought those customs and implanted them here among us, and took what was ours. They made us vote in the community to elect someone, but the longko is not someone elected by the community. The longko is a spiritual being, whose gift and lineage is to serve as an authority. (interviewee 17)

> They already brought you the school, the church, the post, everything. The state today places rules on you and forces you; obligations to fulfill and duties to do. Furthermore, you have very little right in the face of that. The rights for us Mapuche are very, very few. So, you have practically no rights, but you have many duties to fulfill toward the state. (interviewee 8)

For many interviewees, the Mapuche people are tied to territory, and this territory no longer has space to develop. Thus, alternatives must be sought for a new form of articulation between Chilean and Mapuche societies:

> I am a farmer, but nowadays that is ending because there is no more space. Perhaps our grandparents had a decent amount of land, but then more and more people were born, the same land was divided so that everyone had enough, and the pie shrank. Then you can no longer raise animals; you have no pasture or fodder for your animals or crops. You can't even grow crops. So, you must commit yourself to small vegetable gardens, small things, or cleaning the streets as I do now. (interviewee 14)

The respondent also mentioned that it has been a great tragedy for the Mapuche people, generating significant pain and desolation, but that in the course of time the ideas of vindication of their condition as a people are still in force:

> It is not a bad thing that the Chileans are next to us, but how do we balance this, how do we not run over each other, how do we not hit each other? That is the problem; that is the way it is. So, we must keep on recovering and fighting for our people. (interviewee 14)

Another interviewee suggested some solutions:

> The state must educate itself too. Resources and education must be sought for the implementation of new projects and new systems. We must search for a new world of true development, not pollution because it is the cheapest thing to do. For them, it is cheaper to destroy the forests, rivers, or streams that feed the rivers. However, the effects in the future will be catastrophic for the planet, not only for the Mapuche. (interviewee 2)

To summarize, the three themes discussed above interlink with one another, forming a remarkable unity of meaning that implies the presence of a people defeated by war, reduced, and colonized. However, their power lies in the right to be considered a society prior to discovery and colonization that, despite the ethnocidal processes, continues to be a people with a history, an identity, and a projection. Thus, "struggle" is the metaphor that has accompanied the history of the Mapuche people to this day.

Conclusion

Three themes repeatedly emerged from the analysis of the interviews, connecting the perception of the existing situation of the Mapuche people with processes of colonization and the transgression of their fundamental rights, particularly in terms of politics and health. These themes relate to the focus of Collective Health in Latin America on all aspects of social, political, and economic rights that allow the right to health and to the focus of Latin American interculturality in the health field to highlight the knowledge and priorities of Indigenous people. The first theme involves a perceived sense of plundering and extractivism of ancestral or pristine territories as a state policy has been present for centuries. Second, far-reaching changes in the ecosystem have generated transformations in the Mapuche way of life and their relationship with the environment.

The third theme is the Chilean state's colonialist approach, which does not assume the presence of this Indigenous nation in its territory.

Several issues determine the complexity of the interaction between the Mapuche people and the Chilean state with regard to their right to health. The Mapuche paradigm of health and well-being—whose principles differ radically from those of westernized Chilean society—is at the core of this interaction. The Mapuche people have a holistic and integral conception of the synergic coexistence between humans and nature, both of which have a spirituality and identity.[24]

During the Spanish conquest in Chile, land was interpreted as an asset to be expropriated, capable of exploitation for the empire's benefit or for the benefit of individuals who assisted these aggressive strategies. It came to be valued only as a material asset or simply as a commodity to be traded on the international market. The persons inhabiting these territories were not regarded as people; therefore, they were killed or enslaved without rights.[25]

This historical legacy of the exploitation of natural resources has endured, with different facades, up to the present day. Powerful economic interests continue to value Chilean territory (including that of the Mapuche), which is still depicted as pristine and abundant in natural resources, as a source of economic profit. Consequently, the Mapuche cosmovision of health, well-being, and territory collides with an economy-based and extractivist perspective of space, to the extent that Indigenous people are punished, suffer diseases, endure damage to their spiritual well-being, or are left in a state of poverty.

The results of our study suggest the presence of a profound extractive paradigm regardless of the administration in power, which indicates that this is a phenomenon rooted in the very essence of Chilean policies. Through our interviews with members of the Mapuche community, we can perceive the absence of their participation in the realms of policy. The Mapuche people demand recognition and respect as historical subjects because they are the natural owners of the territory in dispute.

In this context, we can see a historical policy of extermination of the Mapuche cultural identity, especially because the state is not protecting the rights of the country's Indigenous population, as it is obliged to do under international human rights law. The changes generated by the state to Indigenous ecosystems have had a transcendental repercussion on the life of the Mapuche people, especially their health.

The current constitutional process underway in Chile is of utmost importance for the country's Indigenous peoples, as it holds the promise of respect for plurinationality, interculturality, and the rights of nature. Nevertheless, the adoption of such a constitutional framework is still far from reality. The Mapuche people are participating in this constitutional process in order to promote a better understanding of their Indigenous rights.

Finally, to conceive health as a cultural right of Indigenous people implies an ethical and moral duty on the part of the Chilean state, and all strategies to accomplish this goal must be through participatory processes involving Mapuche authorities.[26]

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Toward an Integrated Framework in Health and Human Rights Education: Transformative Pedagogies in Social Medicine, Collective Health, and Structural Competency

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Abstract

Global health equity is at a historically tenuous nexus complicated by economic inequality, climate change, mass migration, racialized violence, and global pandemics. Social medicine, collective health, and structural competency are interdisciplinary fields with their own histories and fragmentary implementation in health equity movements situated both locally and globally. In this paper, we review these three fields' historical backgrounds, theoretical underpinnings, and contemporary contributions to global health equity. We believe that intentional dialogue between these fields could promote a generative discourse rooted in a shared understanding of their historical antecedents and theoretical frameworks. We also propose pedagogical tools grounded within our own critical and transformative pedagogies that offer the prospect of bringing these traditions into greater dialogue for the purpose of actualizing the human right to health.

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Introduction

Health workers concerned about the human right to health have reason to be wary as they observe the world around them. Despite a pandemic-triggered global economy slowdown, human consumption continues to generate dangerous levels of greenhouse gasses, pushing carbon dioxide levels to their highest in three million years.[1] During the first two years of the COVID-19 pandemic, profit-driven economic systems crowned a new billionaire every 30 hours while pushing one million people toward extreme poverty every 33 hours. Forty of these new billionaires are pharmaceutical executives.[2] Colonial imprints, white supremacy, and racial capitalism contours and textures both public and private care systems in ways that create patterns of advantage for white-identified and wealthy individuals and disadvantage for (largely poorer) black- and brown-identified individuals in their encounters with COVID-19.[3] The consequences of these upstream forces are health inequities experienced as biological pathology. By upstream, we refer to the social, political, and economic contexts that structure society and are "manufacturers of illness," such as profit-making institutions.[4] Generative mechanisms in society that positively influence well-being are also examples of upstream social forces, such as equitable transportation, healthy rivers and wetlands, and community practices imbued with an ethos of care.

The recalcitrant persistence of health inequities experienced across both local and global contexts has intensified interest in frameworks that claim to diagnose the root causes of these inequities accurately. Prominent among these interdisciplinary fields are social medicine, collective health, and structural competency, all of which also offer a complementary set of prescriptions to remedy inequitable outcomes.[5] Some argue that the intensified interest at this moment is simply a cyclical rediscovery of historically well-described relationships between oppressive social conditions that structure risk for illness.[6] Others believe that the intensified interest and energy, pressured by the emergency context of climate catastrophe, ongoing racial injustice, and a global pandemic, signal something different. They hold the hope that disruptive and generative social change will move the global community toward actual fulfillment of article 25 of the Universal Declaration of Human Rights, which states that "everyone has the right to a standard of living adequate for the health and well-being of himself and of his family."[7]

Social medicine, collective health, and structural competency share core commonalities in their assertion that health is a human right generated not in the biological domain but in the upstream determination of health. This is often akin to the contemporary reference within human rights literature to civil, political, social, cultural, and economic rights. All three of these fields focus on the (re)production of health and systems of care, as well as the political economies that aid or obstruct the realization of public health as a social good. They are each interdisciplinary fields linked with social change projects with broad agendas encompassing the social response to societal ills. All three grew out of academic contexts, and their adherents publish on and organize thematic conferences focused on health justice.

Despite their shared ideological interest in health justice and remedying health inequities, practitioners and scholars in the fields of social medicine, collective health, and structural competency engage in minimal dialogue. Possible reasons for the lack of dialogue include their origins in different geographic, linguistic, and historical contexts, territorialism, academic advancement linked to the generation of novel concepts and language, and the belief that new conceptualizations expanding beyond existing theories and actions are required to eliminate health inequities. Whatever the reason, the lack of exchange and engagement diminishes the possibilities of relationship-building, theoretical expansion, imaginative problem-solving, and the collective building of power needed for social change toward health justice. In short, we believe that the lack of dialogue isolates and minimizes the potential for all three to substantively contribute to the movement seeking to ensure health as a human right for all.

In this paper, our goal is to ignite inten-

tional dialogue among these three fields by (1) juxtaposing their definitions, geographic and historical journeys, and key frameworks and themes, (2) proposing that transformative pedagogy offers one strategy to foster dialogue, and (3) providing concrete examples of what such pedagogy might look like. We illustrate these points by drawing on our collective experience as a transnational group of social medicine educators and practitioners.

Contemporary summaries of social medicine, collective health, and structural competency

We first turn to an examination of the three fields—social medicine, collective health, and structural competency—that highlights the history, central tenets, and theoretical influences of each.

Social medicine

Social medicine is an interdisciplinary field that is over a century old. In the early to mid-19th century, European countries faced many social challenges, including increasingly low wages for the working class, poor working conditions, and a lack of housing and sanitation facilities. These population outcomes alarmed a group of reformist French physicians and hygienists to investigate the relationships between health problems and social conditions.[8] They quickly realized the pervasive influence of social factors on health and disease. German pioneers of the field promoted health care reform after the revolution in March 1848. They proposed three basic principles regarding the academic and practical aspects of social medicine: (1) the health of the population is a matter of direct social concern; (2) social and economic conditions have an important effect on health, disease, and the practice of medicine, and these relations must be subjected to scientific investigation; and (3) steps must be taken to promote health and to combat disease, and the measures involved in such action must be social as well as medical.[9]

Social medicine was introduced to Latin America and the United States in the 20th century (though it has historically had limited uptake in the latter setting owing in significant part to a persistent political aversion to "socialist" forces in the medical industrial complex).[10] This marked a "golden age" of social medicine during troubled times throughout the Latin American region, where local institutions of authority were coopted by transnational interests at the expense the common people. Leaders thus emerged from Chile, Brazil, Cuba, Ecuador, and Argentina to advance theories on the social roots of illness and action-oriented initiatives.[11] This field has also taken inspiration from intersecting fields of liberation theology, empowerment practices in popular education, political revolutions in Cuba and Nicaragua, and a repressed peaceful transition to a socialist paradigm in Chile. Social medicine contrasts with public health "in its definitions of populations and social institutions, its dialectic vision of 'health-illness', and its stance on causal inference," offering analyses that go beyond identifying relatively static mono- or multi-factorial accounts of decontextualized risk factors for health-illness and offering "a more complex approach to causality, in which social and historical conditions receive more explicit emphasis."[12] Social medicine traditions have advanced shared ideals of democracy, egalitarianism, and capacity- and community-building—all ideals grounded within a tradition of *praxis* (reflection and action upon the world in order to transform it).[13] A strength identified within social medicine is the emphasis on the linkage of theory and practice, as leaders have emphasized theory that "both informs and takes inspiration from efforts toward social change."[14]

More recently, at the Social Medicine Consortium conference in 2016 in Minneapolis, United States, a global group of educators and practitioners defined social medicine through consensus as a practice that integrates (1) understanding and applying the social determinants of health, social epidemiology, and social science approaches to patient care; (2) an advocacy and equity agenda that treats health as a human right; (3) an approach that is both interdisciplinary and multisectoral across the health system; (4) a deep understanding of local and global contexts which ensures that the local context informs and leads the global movement;

and (5) voice and vote of patient, families, and communities.[15] Some scholars at the intersection of Latin American social medicine and collective health have proposed a more active language focus on the social *determination* of health as a focus on the dynamic nature of how health-illness is (re) produced.[16]

Collective health

Collective health emerged in Brazil in the 1970s as an interdisciplinary field focused mainly on epidemiology, social sciences in health, and health policy, planning, and management. While largely centered in Brazil at its inception, collective health has grown in importance throughout Latin America, with particularly strong threads emerging in Argentina, Uruguay, and Ecuador in the 1990s. The field was born out of the medical education reform project of preventive medicine and the broader, recursive historical movement of social medicine. It has been connected to grassroots struggles for democracy and health reform movements. Collective health views health and disease as a social process and "investigates the production and distribution of diseases in society as processes of social production and reproduction." It attempts to understand the forms with which society identifies its health needs and problems, looks for an explanation, and then organizes itself to face them.[17]

A strength identified within collective health has been the proposal to organize in both horizontal and vertical directions. The horizontal organization of collective health refers to a social movement oriented toward the professional health-allied community, as well as lay people across society advocating for health as a human right. Vertical organization refers to the intentional development of subject-matter experts in the field such that specialized knowledge can be brought to bear on more complex problems.[18] Thus, collective health has strength in its inherent value of "democratizing" the arena of health as an expanded human right to all stakeholders. It commits to a collective praxis of the social determination of health in a way that is inclusive to experts and common citizenry alike, in horizontal and vertical levels. This is in contrast to social medicine, which has been described as having a "key aim ... to work against vertical approaches that have historically dominated global health interventions."[19]

Structural competency

Structural competency is also a relatively new curricular framework for training health professionals (with predominant historical roots in the United States) to recognize and respond to disease and its unequal distribution, which comes about as the outcome of harmful social structures such as policies, institutions, and systems. Structural competency explicitly engages with the root causes and the "structural violence" naturalized and (re) produced within the status quo. Structural competency was initially developed as a framework to reform medical education paradigms in ostensibly domestic Global North settings with no apparent specific focus on global health.[20] However, it is increasingly being put forth as one response to "decolonize" global health and meaningfully engage with structural drivers of global health inequity.[21]

Structural competency offers strengths in its proposed framework of sub-competencies for global health education (a relatively recent development with structural competency, as its gaze was historically focused on local medical education endeavors) developed by scholars from the Global North and Global South who have developed and taught curricula related to global health, social medicine, and structural inequality. These sub-competencies include being able to

> *(1) describe the role of social structures in producing and maintaining health inequities globally, (2) identify the ways that structural inequalities are naturalized within the field of global health, (3) discuss the impact of structure on the practice of global health, (4) recognize structural interventions for addressing global health inequities, and (5) apply the concept of structural humility in the context of global health.*[22]

One key strength within structural competency is that practitioners have demonstrated a remarkable ability to build cross-institutional and -organi-

zational relationships via their development and delivery of structural competency training to diverse audiences of health care professionals.[23] We highlight the inclusion of sub-competency 5 of structural humility—"a self-reflective approach to addressing the structural determinants of health that requires partnering with individuals and communities to inform understandings of structural violence and to explore how best to respond to it."[24] We feel that it relates closely to our pedagogical localization of the "personal" within our 3Ps educational model described in further detail below. Despite scholars proposing concrete sub-competencies within this field, there remain identified needs to "further refine and operationalize the competencies proposed here into curricula, to develop relevant pedagogy, and to evaluate its effects on trainee knowledge, skills, and real-world impact."[25]

Table 1 summarizes each of the three fields. This work is not a comprehensive review of the fields but rather an examination of how they have contributed to the broader social movement of health and human rights. Significant overlap and interconnection exists between these fields.

In summary, social medicine, collective health, and structural competency are interrelated, interdisciplinary, evolving fields that have recursively grappled with health inequities in their unique histories against increasingly globalized oppressive phenomena impacting historically marginalized and dispossessed communities. There lies an opportunity within global health equity as a social change project to develop a common language and integrated framework for analysis within these fields toward more concrete and collaborative curricular design and evaluation oriented toward transformative learner outcomes linked with social change. Collective health has proposed a "democratized" arena of horizontal and vertical levels of knowledge and practice such that health can be more broadly conceptualized as an expanded human right and such that change can be facilitated by more specialized agents according to the complexity of situations. Structural competency has proposed structural humility such that structural

interventions might be more readily adapted and accepted to diverse localized contexts according to social, cultural, and political differences. Social medicine has proposed a linkage between theory and practice (praxis) such that theory both informs and takes inspiration from collective social change efforts.

Transformative pedagogy and building critical consciousness

Given the cross-disciplinary commitment to social change shared by social medicine, collective health, and structural competency, educating practitioners across all three traditions requires pedagogy that catalyzes learner transformation. Jack Mezirow and Edward Taylor define transformative learning as "learning that transforms problematic frames of reference to make them more inclusive, discriminating, reflective, open, and emotionally able to change." They contend that transformative learning requires a combination of individual experience, critical reflection, dialogue, holistic orientation, awareness of context, and authentic relationships. Ultimately, transformative learning, "require[s] that the learner make an informed and reflective decision to act or not."[26] In other words, success in transformative learning is based not on cognitive measures but rather on learner action or inaction in the world. The central evaluative question following a transformative learning experience then becomes not what knowledge has been gained but rather: Are the learners now acting and engaging differently with themselves and the world around them?

Transformative learning experiences create the conditions for the emergence of critical consciousness. Drawing on the work of Paulo Freire, we understand critical consciousness to involve problematizing the reality of the world in its causal and circumstantial correlations; awakening to the totality of the world and one's place in it; recognizing the self as an active subject in the world working with other subjects to transform the world; and expanding one's sense of possibility and imagination through a gritty relationship with the world. Freire

posited that critical consciousness arises through an iterative process of de-coding in which "the consciousness … rebuilds its power of reflection in the 'entering into' of present understanding which progresses towards a new understanding."[27] Critical consciousness, though, is not just a heightened state of awareness about the sources of the world's ills. Rather, it is the coupling of that heightened state of awareness with an awakened sense of one's agency to transform those ills.

Transformative learning that cultivates critical consciousness requires deconstructing traditional "banking" models of education that treat learners as passive receptacles for information dumping and conceptualize the body and mind as separate agents.[28] Traditional human rights and global health education models often align with Western banking models of education that exist "as an arena of domestication, where abstract knowledge and its constructions are decontextualized, disembodied, and objectified."[29] Domesticating educational processes intensify both social contextual and bodily estrangement, which can "cause false dichotomies that alienate students from their material world—the only true realm from which liberatory education can be forged."[30]

If we genuinely seek human rights education with liberatory potential, critical attention and labor must be put toward human rights education that counters domesticating forces. Education

TABLE 1. Comparative overview of social medicine, collective health, and structural competency

	Social medicine	Collective health	Structural competency
Definition	Social medicine is an approach to health that recognizes the centrality of the social and structural determination of health, integrates social theory to understand social forces that marginalize and harm communities, and builds collective power to challenge oppression and support the struggle for social justice.*	Collective health attempts to understand the forms with which society identifies its health needs and problems, searches for an explanation, and organizes itself to face them. It focuses on the production of practices of health promotion and disease prevention. It is a "scientific field in which knowledge about the object 'health' is produced and where distinct disciplines that see the object from many angles work" … "they view the field as a sphere of practices, in which 'actions are performed in different organizations and institutions by diverse agents (specialized or not) inside and outside the space that has been conventionally recognized as the 'health sector.'"†	"Structural competency is the trained ability to discern how a host of issues defined clinically as symptoms, attitudes, or diseases (e.g., depression, hypertension, obesity, smoking, medication 'non-compliance,' trauma, psychosis) also represent the downstream implications of a number of upstream decisions about such matters as health care and food delivery systems, zoning laws, urban and rural infrastructures, medicalization, or even about the very definitions of illness and health."‡
Historical origins and geographic extension	The term "social medicine" was coined by French physician Jules Guerin in 1848. Rudolf Virchow, a German pathologist who examined illness-generating social conditions in the mid-1800s, is regarded as a founder of the field. Their ideas spread to Latin America in the early 1900s and eventually spread to Africa and Asia in the mid-1900s. Social medicine has also informed social movements to varying extents in East and South Asia, Africa, and Western Europe, often as a consequence of and response to (post)colonial imperialism and transnational corporate hegemony.	The field of collective health emerged in Brazil in the context of an authoritarian regime in the 1970s and is informed by antecedent fields of social and preventive medicine. Widely influenced by Freirean pedagogies of critical consciousness-building and praxis, it is invested in the democratization of health care, of the state, and of society more broadly. The field spread throughout Latin America in the 1990s and is commonly referred to interchangeably with Latin American social medicine.	Structural competency was first proposed in 2014 as a curricular framework for medical education. Its curricula have been deployed mainly within US medical schools and have yet to spread to other regions or continents.

rooted in dialogue is central for accomplishing this. As noted by Denis Goulet in his introduction to Freire's *Education: The Practice of Freedom*, "The mark of a successful educator is not skill in persuasion—which is but an insidious form of propaganda—but the ability to dialogue with educatees in a mode of reciprocity."[31] In our experience, dialogue must, however, expand beyond its traditional

conceptualization as two cognitive beings engaged in an exchange of information. Generating critical consciousness requires us to envision dialogue as a dynamic process that involves the circulation of information, sensation, and emotion between minds, bodies, hearts, and place/land. We must welcome the invitation toward a revolutionary praxis of the body in which we recognize how the body plays

TABLE 1. *continued*

	Social medicine	Collective health	Structural competency
Representative organizations and collectives	Social Medicine Consortium EqualHealth Global Social Medicine Montefiore Primary Care and Social Medicine Program Harvard Medical School Department of Global Health and Social Medicine ALAMES: Latin American Social Medicine Organization	ABRASCO: Brazilian Association of Collective Health CEBES: Brazilian Center for Health Studies Brazilian Congress of Collective Health	Virtual platform Structuralcompentency.org has served to diffuse and integrate structural competency throughout US medical training programs
Guiding frameworks and themes	Examines the impact of oppressive social forces (e.g., racialized capitalism, heteropatriarchy, imperialism, and colonialism) on health Utilizes models of community organizing to build power Seeks to forge global solidarity and liberation	Offers a paradigm of the social determination of health as an active, ongoing, dynamic process within a collective, holistic social totality Principally focused on collectively organized action to confront, understand, and modify social processes so that they protect and improve—rather than harm and degrade—human and natural life	Identifies five core competencies: 1) recognizing the structures that shape clinical interactions 2) developing an extra-clinical language of structure 3) rearticulating "cultural" formulations in structural terms 4) observing and imagining structural interventions 5) developing structural humility
Key observations	Social medicine is an adjacent discipline to sociology. It has developed into a rich, diverse field rather than a homogenous tradition. Theory has often remained linked to action through praxis. Social medicine groups have linked their policy research with organizing efforts aiming to change power relationships. Practitioners have prioritized "grassroots" or "bottom-up" approaches to enacting change, as well as lateral translation of successful approaches developed in one place and adapted for use in another. Contrasts with public health in offering a more dynamic portrayal of health-illness dialectic, as well as explaining differential effects of social and cultural contexts situated across diverse geographic and historical settings.	Interdisciplinary field with major contributions from epidemiology, social sciences in health, and health policy, planning, and management. Proponent experts have proposed an integration of collective health within the broader field of health on the horizontal and vertical levels in an effort to democratize practices of health. Works horizontally through advocacy of health as a human right in professional and lay contexts. Experts who produce more sophisticated knowledge intervene in more complex situations in a "vertical" fashion.	Developed by scholars in Global North and South who have also taught social medicine. Adapted for clinical practice as a critique of clinical competence and cultural humility as decontextualized explanations that risk naturalizing structural inequalities. Offers pedagogical proximity to the current structure of modern medical education (though mainly in Global North settings at this time), which utilizes a competency-based framework for evaluation.

* Many definitions of social medicine have been offered over time. This definition is a summary version of the five-point Social Medicine Consortium definition described above and is our working definition.
† A. Osmo and L. Schraiber, "The Field of Collective Health: Definitions and Debates on Its Constitution," Saúde e Sociedade 24/Suppl 1 (2015).
‡ J. Metzl and H. Hansen, "Structural Competency: Theorizing a New Medical Engagement with Stigma and Inequality," Social Science and Medicine 103 (2014).

a significant role in making sense of the material conditions and social relations of power that shape human and non-human life and land.

A model of social medicine education

EqualHealth has centered transformative pedagogy since its origins. As a collective of health workers and educators from both Global North and Global South contexts, a handful of us first came together in 2010 in Northern Uganda, dissatisfied with traditional educational content and the missed opportunities for relationality among peers in our global health endeavors. For more than 10 years, we, the authors, have taught social medicine in three different institutional and sociopolitical contexts—Sub-Saharan Africa, particularly Uganda and Rwanda; Haiti; and the United States. Over this time spent implementing and reforming the social medicine courses, the learners' reach stretches across four continents of Africa, Asia, North America, and Europe. It is, in fact, the transnational nature of our relationships and work that brought us into encounter with these three fields, whose roots and histories lie in diverse geographic contexts. Today, EqualHealth is a nonprofit organization that centers building critical consciousness and collective action globally in pursuit of health equity, with intentional anchors in Uganda and Haiti. We, the authors of this paper, from Uganda, Haiti and the United States, among other colleagues, have taken up leadership roles within EqualHealth. Our programs include social medicine courses in Uganda, Haiti, and the United States, as well as the Campaign Against Racism, a global action-focused collective with 21 member-based chapters from nine countries seeking to dismantle racialized capitalism in health care.

Our social medicine courses are the central mechanism for our transformative pedagogy work. These courses seek to engage students in the praxis of health equity, the social and structural determination of health, the principles and practice of global health in local settings, and leading change. They are topically organized to foster an examination of oppressive social forces and liberating practices.

Oppressive social forces (e.g., heteropatriarchy, racism, racialized capitalism, settler colonialism, and imperialism) are historicized and politicized to debunk the standard perception that they are naturally occurring, essentialized phenomena of the world.

Our original courses consisted of three- to four- week immersion programs in Uganda and Haiti, with learners from the Global North and the Global South living and studying together for the immersive period. In recent years, due to the global COVID-19 pandemic and heightened concern over the climate impact of global travel, we have adapted our curricular structure and content to offer three simultaneous social medicine courses in the United States, Uganda, and Haiti. Within these courses, we create space for intentional transnational dialogue across the parallel cohorts, seeking to foster conditions to build solidarity and mutual understanding of the differential effects of globalized social forces. Across all three sites, we explore what creating conditions for healing, health, and safety means in our lived communities through exposure to community organizing, mutual aid and community-based care, embodied healing practices, the arts, and storytelling. This content provides rich opportunities to develop the organizing, relational, and creative skills that are foundational for advancing health equity in partnership with communities. Detailed descriptions of the course content have been published elsewhere.[32]

EqualHealth grounds its learning model in the 3Ps—praxis, personal, and partnership—as a means of fostering transformative outcomes for learners, teachers, and practitioners alike. We aim to destabilize traditional hierarchies of power found in global health communities by invoking practices of mutuality and reciprocity, where all participants can engage one another as peers. This learning model aims to build critical consciousness, described above. In practice, place-based and embodied learning has inspired students to identify, analyze, and strategize to resist repressive policies, albeit functioning within an authoritarian system.[33]

The notion of praxis is inspired by Freire, in which pedagogues are co-creating the conditions

for a constant interplay between reflection and action (alongside learners and other stakeholders).[34] Educators are present not to deposit knowledge into students' minds but rather to co-create knowledge alongside participants. Everyone involved in education, then, is a learner, and learning activities are not just listening to expert speakers, watching films, or reading texts; learning also includes both meaningful dialogue and opportunities to act in the world. The courses intentionally center connections with local community members as well as those from outside the traditional health disciplines to birth creativity, inspire imagination, build relationships, and foster connections essential to engaging social forces that determine health.

Attention to the personal is based on the notion that critical self-awareness enhances our abilities to examine and act upon harmful social structures. It is a foundational component of a "revolutionary praxis of the body," as it explicitly invites learners to utilize their senses and their personal subjective experiences of oppression and advantage to reflect upon the (re)production of social forces.[35] Rather than merely reflecting on words in a text or theories that explicate the interlocking systems of oppression, we invite learners to share their lived experiences and center them in their analysis and in relationship-building with others in the learning space. The course thus integrates critical reflection upon personal and collective experiences operating within interlocking systems of oppression, such as racism, classism, ableism, and heteropatriarchy. Of note, pedagogy, even when critical, can and does reproduce harm if extreme care is not taken to attend to "power-over" dynamics that unfold in classrooms composed of learners from the Global South and Global North.[36] As facilitators, attentiveness to the unintentional reproduction of patterns of harm is critical for creating safe learning spaces that potentiate the emergence of new forms of relationship based on mutuality, care, dialogue, and trust.

Finally, the value of partnership is foundational. Our understanding is that authentic partnerships across differences must be thoughtfully co-created and nourished in order to advance equity and ap-

proximate social justice. Too often, classrooms and educational processes replicate power dynamics already apparent in society, as those advantaged with social privilege and power "outside of the classroom walls" are given more opportunity to amplify their ideas and theories and make consequential decisions—praxis—than those from marginalized communities. In the context of global human rights education, a significant dichotomy is often amplified between those from the Global North and those from the Global South; and between those perceived as donors versus those perceived as recipients of assistance. Thus, our pedagogical approach is one that continually seeks opportunities for learners to build authentic relationships with one another—relationships that may, with time, evolve into generative partnerships. In the transnational reflection space, learners are invited to share what they witness locally, and then dialogue with a cadre of global learners about differences and similarities across the geographic spaces.

Discussion: A vision for dialogue through transformative pedagogy

While many potential spheres exist to spark interdisciplinary conversation between social medicine, collective health, and structural competency, we, given our position as educators grounded in critical pedagogy, envision one possible path through transformative pedagogy. As discussed above, transformative pedagogy creates a dynamic space that allows for ideas to intersect in a generative manner. When doing so with care, we believe that learners, faculty, and ideas all emerge changed and in deeper relationship. We believe that the same could occur for these three disciplines by intentionally bringing them into a space together and around the proverbial table for conversation.

Fostering such dialogue will require deliberate adaptation of pedagogical tools currently used in our learning environments. Based on our humbling past experiences, we urge educators to deliberately anticipate and continually monitor for unintentional harm that arises among learning communities with diverse identities. This is especially true when

adapting or trialing new pedagogies, such as those suggested below. In Table 2, we identify key pedagogies currently used in EqualHealth's curricula and potential adaptations that aim to foster interdisciplinary dialogue.

Social medicine, collective health, and structural competency are interrelated, interdisciplinary, and evolving fields that have recursively grappled with health inequities in their unique histories against increasingly globalized oppressive phenomena impacting historically marginalized and dispossessed communities. There lies an opportunity within global health equity as a social change project to develop a common language and integrated framework for analysis within our fields toward more concrete and collaborative learner outcomes in order to better realize the human right to health. Particularly, we highlight a complementary strength from each of these fields. Among other fields of study dedicated to advancing the

TABLE 2. Pedagogic strategies to foster dialogue

Pedagogy	Description	Example of current use	Potential adaptation
Disciplinary definition and social theory introduction*	Social medicine is defined and key social theories (unintended consequences of purposive action, social construction of reality, biopower, social suffering, racial capitalism, coloniality, Black radical feminism, intersectionality) are introduced and learners identify examples seen in their local contexts. This is accomplished in didactic and participatory fashion.	A series of images and stories connected to social medicine are shared. A descriptive introduction to the social theories is also provided. Learners then take an observational walk in small groups through a clinical context and identify examples that illustrate the theories. They are also asked to develop their own definition of social medicine.	Images and stories related to health are shared, and learners are asked to place each example in a bucket corresponding to the field that most closely connects. Learners are asked to write their own definition of social medicine, collective health, and structural competency. Learners are asked to consider which theories feel most important for each of the disciplines.
Theater of the oppressed†	Augosto Boal's image theater is used to promote non-cognitive exploration of key concepts in social medicine. Forum theater is used to rehearse intervening on and disrupting oppression.	Using their co-learners as clay, learners sculpt "charity," "development," and "social justice." Learners observe a scene depicting harm occurring when an individual facing housing insecurity interacts with the health system. As "spect-actors," learners intervene to attempt disruption of the oppression.	Learners sculpt key ideas from each of the fields: "praxis" from social medicine; "structural humility" from structural competency; and "vertical and horizontal dimensions of collective health" from collective health. Learners are then invited to put the three concepts into dialogue based on the theatrical embodied experience.
Solidarity visits	Community leaders guide learners through spaces with historical connection to social forces that create conditions for health or disease.	Learners in Uganda visit Fort Patiko, a site in Northern Uganda connected to slave trading and European colonialism. Students in Haiti visit the rural community of Boucan Carré, a remote place where people live without potable water, enough food, and health care access. Students experience the health impact of structural forces. The goal is to dismantle the roots of social suffering and diseases by raising empathy and curiosity.	Facilitators intermittently pause during the visit and invite students to consider whether and why information conveyed would be considered valuable to social medicine, structural competency, and collective health.
Walk the talk	Learners participate in a facilitator-guided visit to know the people and the environment where they live, learn, and practice.	Learners in Uganda walk through communities surrounding their clinical environments. A facilitator prompts learners to pay careful and critical attention to surrounding landmarks, housing, environment, social services, and economic activities in the area.	Learners move out of the classroom space and walk the journey of the patients, community health workers, and other health care providers. Learners are asked to reflect on how the conditions in which people are born, live, and grow influence access to services and the health outcomes.

agenda of health and human rights, social medicine, collective health, and structural competency are uniquely positioned to provide foundational frameworks, content, and methods of global health equity analysis and action. Social medicine's praxis—theory and action—both informs and takes inspiration from collective social change efforts. Collective health has proposed a "democratized" practice arena composed of horizontal and vertical levels of knowledge and practice contextualized within an active process of social *determination*. Structural competency has proposed structural humility such that structural interventions can be adapted to diverse contexts across various ecological levels, from micro to macro scales.

As critical and transformative pedagogy-oriented educators and advocates, we identify these three strengths as logical extensions to an equitable human rights education—one that focuses on a social change framework prioritizing personal empowerment, fostering and enhancing leadership, and development of alliances and coalitions.[37] Experts in human rights education have proposed that programming take on an interactive pedagogical approach and have proposed idealized typologies for such programming.[38]

The three identified strengths from social medicine, collective health, and structural com-

TABLE 2. *continued*

Pedagogy	Description	Example of current use	Potential adaptation
Narrative medicine and health‡	Narrative medicine uses slowed, reflective attentiveness to literature, images, and sounds (the arts) to create conditions that deepen our ability as clinicians to share and receive stories. These practices promote connection, affiliation, justice, and healing.	Students in Haiti visit the University Hospital of Mirebalais. Students in Uganda visit Lacor Hospital. In their visit, students engage in dialogue with patients to cultivate their narrative competence to understand stories and identify the root causes of disease beyond biology.	Literature, films, and visual art are curated with the intentional aim of opening up conversation on the boundaries and convergence between these fields. For example, after reading a short poem that explores a spirit of collectivity, learners are invited to write in response to the prompt, "What might you imagine collective health to involve?"
Privilege and assets walk§	Learners line up horizontally and are asked a set of prompts focused on how social and cultural systems that produce privilege and oppression have personally affected their lives. They are instructed to step backward or forward accordingly. Question example: "If one or both of your parents completed a university degree, take one step forward." Following prompts connected to privilege, a second set of prompts are read that focus on assets and strengths.	After considerable trust has been built in a class, learners engage in this activity, followed by a small group discussion that explores how social and structural forces connect to individual experiences of oppression. We also explore the limitations of the concept of privilege.	Structural competency could aid in contextualizing conceptions of interlocking systems of oppression in structural terms rather than cultural terms (it could also aid in interrogating how structural inequalities are naturalized in global health settings), and it could also promote an understanding of individual/community assets promotion in terms of "structural interventions."
Embodied or somatic learning**	Practices from the trauma-healing tradition of somatic experiencing are incorporated in order to expand learner curiosity about and connection to their bodies as sources of wisdom. Developing such skills generates capacity for sustained engagement with health justice work.	Learners in the United States join an Indigenous leader for a four-hour visit to sacred Dakota sites in Minnesota that teach the history of white settlement and Indigenous genocide and resilience. Both prior to and during the visit, learners are invited to pay attention to and process how their bodies experience the stories shared.	A trained somatic experiencing practitioner guides three individuals who respectively most closely identify with social medicine, structural competency, and collective health through a somatic session that explores how they experience their work in their bodies and their sources of burnout and resilience.

* A. Kleinman, "Four Social Theories for Global Health," Lancet 375/9725 (2010).
† C. Robinson, Black Marxism (Chapel Hill: University of North Carolina Press, 2021).
‡ F. Fanon, "Medicine and Colonialism," in A Dying Colonialism (New York: Grove Press, 1965).
§ D. Porter, "How Did Social Medicine Evolve, and Where Is It Heading?," PLoS Medicine 3/10 (2006).
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petency together have the potential to spur us to advance the agenda of health and human rights in a more cohesive framework that centers reflexivity, inclusivity, and relational solidarity across diverse historical and geographic contexts. If we are to advance a model of praxis geared toward social justice in global health, then an equity-oriented education and advocacy approach that is rooted in structural humility serves that end. More recently, Felisa Tibbitts has proposed a revised model of human rights education that points to the importance of integrating a reflective and critical stance.[39] This model emphasizes attention to one's own value system, power structures in the immediate and more distant environments, and the human rights framework. In line with Tibbitts, we contend that creating standards and values that uphold health and human rights requires a genuine and honest dialogue that engages, challenges, and questions the learners' worldviews. Tibbitts identifies critical pedagogy as a philosophical "mother" to human rights education that can help "reflect upon, critique, and improve our efforts" in navigating tensions within human rights education as an endeavor mired by controversializing claims such as honoring indigeneity, examining conceptions of universality, and working with hierarchical structures of bureaucracy across private and public spheres. We propose that the lens of transformative pedagogies might be one such productive forum from which to promote further dialogue and offer suggestions. Our educational model rooted within social medicine and within our own principles of the 3Ps—praxis, personal, and partnership—has enabled us to recognize and understand the commonalities across and strengths of each of the three fields: social medicine, collective health, and structural competency. Our proposal for dialogue is not synonymous with a call to collapse or subsume these diverse fields into a standardized or universal framework, but rather to promote generative discussion at the intersection of their unique historical settings and their shared vision of promoting global health equity through interdisciplinary collaboration.

Limitations of this proposed dialogue as envisioned might include a relatively distanced in-terface with epistemologically different frameworks aligned with more "biotechnical" or "technocratic" formulations of global health structures, such as health systems strengthening, health systems administration and finance, global health security, and global health policy and research. Future directions of the proposed dialogue might interrogate how we can promote more coherent ethics across these different fields and local-global settings, as well as how we can design, translate, and evaluate social and structural interventions from educational settings to research and practice settings.

Conclusion

Calls from the field of global health to "decolonize" have been met with a suggestion to promote "dialogical reflexivity" with the aim of decentering Western epistemologies and further learning from Indigenous practices and worldviews of seeing the "whole person (physical, emotional, spiritual, and intellectual) in relationship with other individuals, communities, nations, and the world, guided by values of respect, reciprocity, relevance and responsibility" (note: this proposal for reflexivity diverges from its usual place within qualitative research and is brought closer to individual positionality).[40] "Dialogical reflexivity," similar in overarching principles to our model of the 3Ps, has been framed as comprising elements of "self-understanding, dialogue with peers, and insights-to-action."[41] We join with colleagues in calling for the building of a culture of dialogical reflexivity within the global health community. We thus offer our educational model of the 3Ps, as well as examples of collaborative transformative pedagogies, as a way of raising critical consciousness around oppressive forces. Promoting global health justice requires that we employ tools that aim to deconstruct forces that threaten human dignity with the goal of ensuring health as a human right for all.

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11. Waitzkin et al. (2001, see note 5), p. 1592.

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Promoting Patient-Centered Health Care and Health Equity through Health Professionals' Education in Rural Chiapas

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Abstract

Since 2011, the nongovernmental organization Compañeros En Salud, as Partners In Health is known in Mexico, has worked in collaboration with the Mexican Ministry of Health to strengthen the health care system in the Fraylesca and Sierra Mariscal regions of Chiapas, Mexico. In response to the high proportion of abandoned and understaffed clinics in the area, Compañeros En Salud has developed a program to entice medical students from some of the top medical schools in Mexico to spend their "social service year" in these facilities, where they receive financial support, on-site clinical mentoring, supplies, clinical support tools, and training in global health and social medicine using a structural competency framework. The idea is to provide high-quality health care to a historically underserved

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population through a lens of health as a human right. Although other structurally competent global health curricula have been implemented worldwide, primarily in the Global North, the Compañeros En Salud model is unique in that it combines (1) the facilitation of theoretical lectures based on the Social Medicine Consortium's definition of social medicine, (2) global health case discussion and context-reflective experiential simulations, and (3) exposure to patients who suffer the burden of structural injustice. In this paper, we describe the motivations behind the training model, its holistic approach, and the impact of this initiative after a decade of implementation.

Background

Global health institutions and researchers are mostly based in high-income countries, whereas most global health interventions take place in low- and middle-income countries.[1] Consistent with this, global health curricula are often developed and delivered by Global North institutions and faculty, with 95% of masters of global health programs located in high-income countries, and are mostly available to high-income country candidates who can afford the high fees of these programs and have more facilities to physically access classes.[2] This dynamic often results in global health programs that lack the insights of practitioners working in the world's most underserved and marginalized settings in which global health practice takes place.[3] In addition, many students in global health programs from high-income countries will not end up facing the global health challenges addressed in their studies in their future practice.

To counter the disconnect between underserved settings and global health curricula and between global health students and their future practice settings, there is a need for global health education initiatives to emerge from the Global South for practitioners in the Global South. Instead of considering the Global South as a whole, it is important to develop context-specific curricula that consider the social determinants of health. This can help make global health education more fruitful and eliminate colonial remnants in the global health field, shifting power to local ownership.

On top of this, building global health education initiatives that move away from the public health and human rights orthodoxies prevalent in most US institutions presents a great opportunity to adopt an integrative human rights approach in which civil and political rights, as well as social and economic rights, are given the relevance they deserve.[4] In order to achieve "the right to the enjoyment of the highest attainable standard of physical and mental health," first articulated in the 1946 Constitution of the World Health Organization, more is needed than just health facilities, even if they provide health care services that are of good quality and medically and culturally acceptable. These facilities must be physically and financially accessible to the population in an equitable manner and combined with public health interventions for the prevention and control of diseases. And importantly, the population must participate in health-related decision-making. To achieve this, the right to health should not be seen as an independent human right but as a right that is interdependent with other economic and social rights, such as the rights to work, water, food, housing, education, and nondiscrimination.[5]

Pioneering this approach, Compañeros En Salud (CES)—the sister organization of Partners In Health in Mexico, a nongovernmental organization that receives funds from individuals, corporate donors, and private foundations to provide care to the rural populations of Chiapas—decided to develop a human rights-based global health and social medicine curriculum (GHSMC) adapted to the local

setting of the rural region in 2011. The program is complementary to the work that the organization initiated to support rural outpatient clinics in the Fraylesca and Sierra Mariscal regions of the state in defending health care as a human right, with the premise that quality care must be accessible to all and consider structural factors. Specifically, the curriculum aims to improve the structural competency of *pasantes*, medical students in their mandatory "social service year." In Mexico, as in other countries in Latin America, graduates from medical and nursing school are required to provide one year of "social services" to the government in order to obtain their licenses. This program started in 1936 and has been the main government strategy for staffing clinics in rural places. These professionals are called pasantes, as they "pass by" a community for a one-year period. In the case of medical pasantes, there has been a long debate over whether they are doctors or medical students (as they are technically considered now).[6] Either way, they are often the only providers in rural communities, with little supervision and a lack of ongoing training. Although structural competency is a necessary skill for any health professional, it is especially relevant for those working with underserved and marginalized populations to better understand the social determinants of patients' health.[7] Structural competency has been defined as the ability of health care workers to acknowledge the influence or effects of social, political, and economic structures in people getting sick, as well as being able to respond to them.[8] According to Michael Harvey et al., structurally competent global health education includes the following elements:

> *(1) … the role of social structures in producing and maintaining health inequities globally, (2) … the ways that structural inequalities are naturalized within the field of global health, (3) … the impact of structures on the practice of global health, (4) … structural interventions for addressing global health inequities, and (5) … the concept of structural humility in the context of global health.[9]*

Chiapas is one of the most deprived states in Mexico in terms of structural and intermediary social determinants of health.[10] At the structural level,

the average degree of education is only 7.8 years (versus 9.7 years at the national level), and 84.2% of the working population lacks access to social security, as most work as farmers in the informal sector.[11] Aligned to this, according to the National Institute of Statistics, in 2020, 35.3% of the Chiapas population did not have any form of health insurance or social security.[12] This population has historically been covered by the health services provided directly by the Ministry of Health, which contributed 38.3% of total health expenditure in Mexico in 2020.[13] In terms of intermediary social determinants of health, 49.1% of the population lives in houses without chimneys and uses firewood or charcoal for cooking, and only 47.8% of the population is food secure. All of this is reflected in the state's high multidimensional poverty rate of 75.5%.[11]

These structural factors and precarious living conditions of the population are behind most of the top 10 causes of morbidity in the state: acute respiratory infections, perinatal complications, intestinal infections, urinary tract infections, gastritis, intestinal amebiasis, salmonellosis, otitis, periodontal diseases, and candidiasis. There is also a high burden of noncommunicable diseases, including mental health disorders, although due to the lack of training of health professionals to identify these conditions and of accurate electronic medical records, these diseases are largely under-diagnosed.[14] Moreover, the lack of timely access to quality care is related to a high burden of preventable deaths from these conditions and also from complications during pregnancy, childbirth, and postpartum.[15] Although the current Mexican public health model covers the entire population outside the formal labor market for all health needs at no cost, this is not the case in practice. Chiapas has the lowest number of health specialists in the country.[16] Also, many outpatient clinics in the rural areas of Mexico, where 51% of the population of Chiapas resides, have access only to a pasante completing his or her social service year or are simply neglected.[17] This forces users to travel long distances to seek care, which they often cannot afford or which sometimes takes too long if emergency care is needed, as only

22% of the state's roads are paved.[18]

As mentioned above, the challenging living conditions of the Chiapas rural population make understanding structural competency key for health care providers in the region. However, there are scarce educational curricula in Mexico that train health personnel in becoming structurally competent.[19] Hence, Compañeros En Salud has decided to address this issue through the GHSMC, a curriculum that combines knowledge acquisition, case discussion, and exposure to patients in an iterative process that aims to prepare competent and sensitized professionals.[20] Unlike other global health programs worldwide, this one was created—and is delivered and taught—by professionals working in the same rural underserved settings in their own practices, thus ensuring that the program responds to the needs of local health professionals and patients while also considering the global factors that underlie local health inequities and understanding the right to health as interdependent with other social and economic rights. In this paper, we discuss the Compañeros En Salud approach, its learnings to date, and impact of this initiative after a decade of implementation.

Origins of the curriculum

Chiapas's current burden of disease and socioeconomic indicators require personnel with capacities beyond providing mere clinical care. However, in Mexico, the training of health professionals remains largely clinically focused, centering on the diagnosis of diseases and pharmacological and interventional treatments and generally overlooking how health problems may derive from determinants and social structures that harm marginalized populations.[21]

As mentioned earlier, completing the "social service year" is a requirement for obtaining a medical or nursing degree in Mexico.[22] This requirement entails being sent to a rural area to provide care and often means being responsible for an entire community. Such a responsibility carries the risk that the skills required to respond to the demands of the population and the system exceed those learned during one's medical education. Clinical staff often remember this year as a difficult period without support. Compañeros En Salud seeks to transform the traditional social service year model by complementing this year with a diploma in global health and social medicine in order to allow practitioners to provide culturally competent and dignified clinical care that embraces a human rights-based global health and social medicine approach.

There are multiple reasons why structural competencies are considered fundamental in the curriculum: (1) because the understanding of structural and social determinants is directly linked to treatment success (for example, in the early days of Partners In Health's work in Haiti, the organization realized that malnourished tuberculosis patients would not improve with medicines alone but also needed food); (2) because the reality of the communities served clearly expresses the origin of their health conditions; and (3) because these conditions frequently subject providers to situations of frustration that prevent them from making informed decisions, both for the population and for themselves. For Compañeros En Salud, it is equally as important to have well-trained personnel who can offer quality services as it is to have personnel with skills that allow them to respond to the challenges that the immediate reality requires.

When it was originally created, the GHSMC was geared toward medical providers. However, the curriculum has since extended to nursing, obstetric-nursing, and midwifery providers. This extension has involved restructuring the previous curriculum and incorporating interprofessional training, which has enriched learning and collaboration among the professions. Moreover, as mentioned above, the curriculum is taught by instructors who were former pasantes. This allows instructors to share real-life examples of how theoretical concepts, context, and practice intersect, which maximizes the educational experience.

Early curriculum structure

When it was first rolled out, the GHSMC included two main modules: (1) the social medicine and

global health module and (2) a clinical module that responded to the local burden of disease that included an introduction to locally developed clinical algorithms that not only were evidence-based but also included an adaptation of the clinical decision-making points according to the availability of resources, including medications and logistical barriers.[23]

The first module included a three- to four-hour lecture that introduced global health and social medicine terms and offered a practical portion where pasantes engaged in case discussions, debates, experiential simulations, and reflective sharing. Proximity to the social problems from the field boosted a better introduction of the theoretical terms being learned. This module later incorporated the five points of social medicine as defined by the Social Medicine Consortium, a consortium that includes universities, organizations, and health and non-health professionals aiming to reach health equity:

1. Understanding and applying the social determinants of health, social epidemiology, and social science approaches to patient care,

2. An advocacy and equity agenda that treats health as a human right,

3. An approach that is both interdisciplinary and multi-sectoral across the health system,

4. A deep understanding of local and global contexts ensuring that the local context informs and leads the global movement, and vice versa,

5. Voice and vote of patient, families, and communities.[24]

This definition served as the basis of the lecture topics presented to pasantes until 2020, when the need to restructure the curriculum arose due to the interdisciplinary professionalization of pasantes, the growing need to preserve the clinical topics that were most relevant to the context, and the need to improving pasantes' skills to better communicate with the people they serve and with their colleagues.

Current curriculum structure

To restructure the curriculum, in 2020, the course was evaluated qualitatively to determine the extent to which it was aligned with the local burden of diseases and the extent to which its topics promoted the development of structural competency. This process was carried out in seven stages: curriculum needs diagnosis, definition of modules and themes, integration of modules and themes, profile of speakers, didactics, evaluations, and follow-up strategy. Throughout the restructuring period, the perspectives of pasantes, the administrative team, and the field implementation team were considered. These individuals' recommendations were solicited in relation to the perceived needs of their communities—an approach that, though not ideal, was still valuable as a starting point.

The restructuring was focused on the selection of topics, didactics, health care strategies, clinical follow-up, and responses to health services. Theoretical, conceptual and didactic aspects were considered to offer a comprehensive adjustment to the curriculum.

Finally, the curriculum was restructured to include four modules offered simultaneously, each with theoretical and practical components. The objective was to ensure the standardization of the clinical quality offered by pasantes, with a human rights-based global health approach and institutional values. The four modules are (1) introduction to global health and social medicine; (2) interventions focused on the prevention, treatment, and control of diseases, including sexual and reproductive health topics, ultrasound skills, and mental health topics; (3) management and values for the care of marginalized populations; and (4) tools for resilience and well-being (Figure 1). Before pasantes begin providing care in the community clinics, they are offered a 32-hour theoretical introduction that includes aspects of Compañeros En Salud's context (values, protocols, and functions) and information on the organization's alliances. Of particular interest are its alliances with the government, which allow pasantes to identify the regional

and local response capacity.

The theoretical component consists of two monthly sessions of eight hours each day, which include content from the aforementioned modules. Among the topics of structural competence, the following stand out: relationship of global dynamics between countries and their impact on patients and on their local context, social approach to health and disease, social determinants of health, the human right to health, and the evolution of access to medicines.[25] Moreover, in-person simulations such as the "poverty simulator" emulate the complex structural barriers in which people are embedded. The GHSMC also includes 480 practical hours in the field through community supervision and adaptation to the social context, which is expanded on later in this paper.

One of the key elements of the Compañeros En Salud curriculum is its emphasis on the daily practice of concepts from the four modules. For instance, for module 1, the practical training involves home visits, which allow students to understand the context in which people live, the challenges they face, and their family dynamics, and foster a closer bond between patients and providers. This module also encourages pasantes to follow up with patients who have been referred to specialized care in the capital city, which gives pasantes a better sense of what it means for a patient to miss a workday, make family arrangements, and navigate the health system in order to show up to a consultation in the city. For module 2, on-site clinical supervision promotes competency-based learning by allowing pasantes to model clinical skills such as ultrasound techniques and mental health consultations alongside a supervisor. For module 3, the use of interpersonal skills for communicating with the clinical team and with patients' families offers pasantes the opportunity to engage in horizontal conversations among nurses, physicians, and community health workers and to learn how to allocate workloads or organize roles when attending to a patient's emergency. For module 4, intrapersonal skills are taught for situations in which pasantes witness structural violence affecting their patients, which oftentimes may cause pasantes to experience feelings of helplessness,

requiring them to strengthen their resiliency skills and structural competency for emotional processing. This process is often supported by pasantes' supervisors in a genuine way, since they have experienced similar situations before.

Furthermore, the structural competencies are transversal in the modules; the proposed didactics include discussion spaces that allow pasantes to integrate knowledge from their own experiences and those of their peers. In addition to familiarity with concepts of structural competency, being an effective health care practitioner in culturally and ethnically diverse Mexico requires complementary skills such as cultural humility, clinical competency, active listening, and leadership. The GHSMC aims to develop these capacities as well and, by doing so, reduce barriers to accessing quality care.
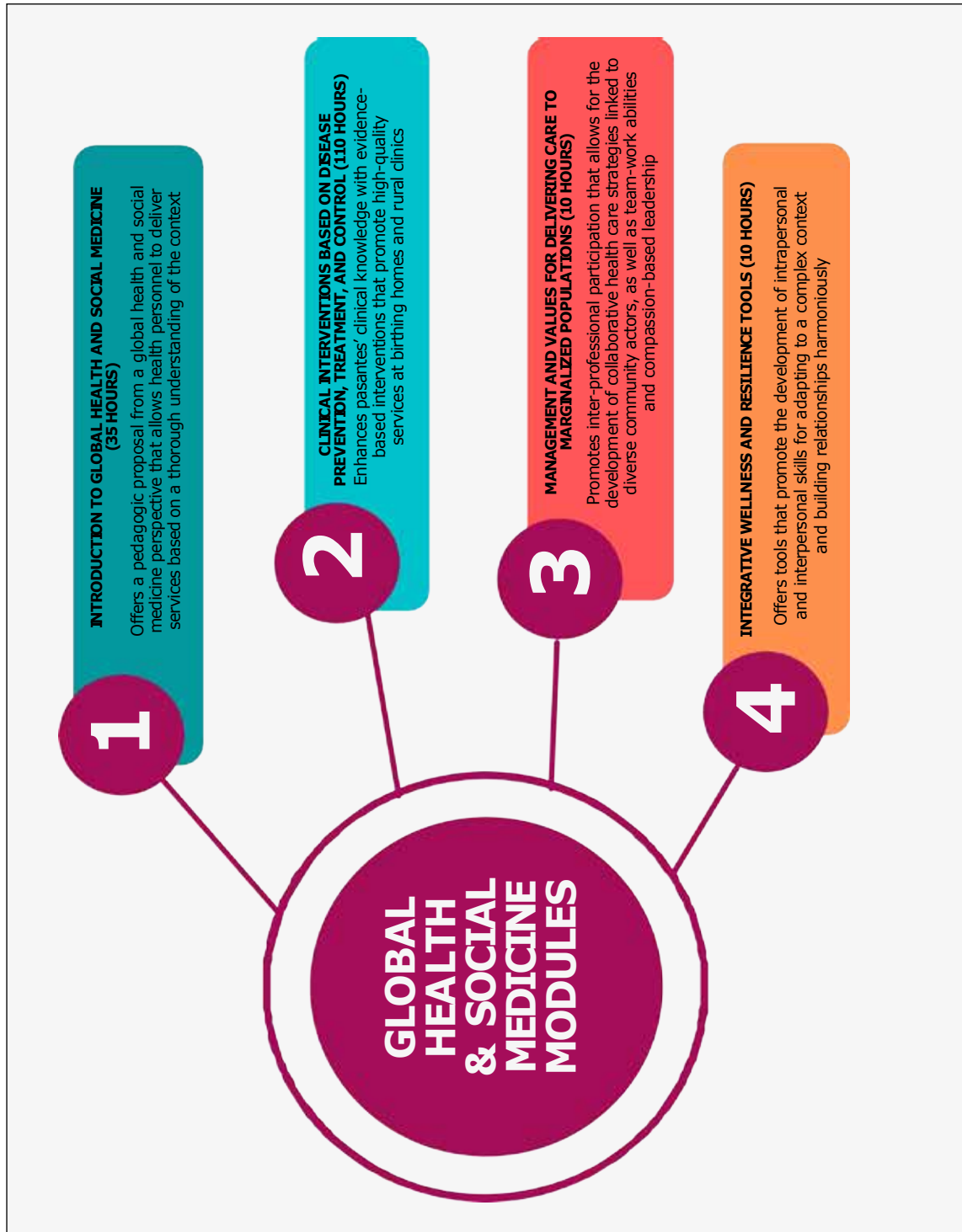
Finally, as part of the curriculum's evaluation of students, both qualitative and quantitative criteria are considered. The former are meant to assess the attitudes and soft skills expressed by trainees during care and teamwork. The latter are meant to assess students' theoretical knowledge through written exams. Additionally, by the end of their service year, pasantes are invited to give a presentation that depicts their experiences, reflections, and learnings.

Complementary field supervision

The GHSMC learning process is complemented by field supervision in which pasantes are supported on site by a clinician who formerly worked as a pasante. This allows students to have a smoother immersion into the rural community and understanding of the social factors impacting them, as the supervisors have a thorough perspective of both the local burden of disease and the social issues affecting the community.

Generally, this supervision is performed by an obstetric-nurse or a medical supervisor who oversees all of the care delivery interventions and assures the quality of the delivery through feedback. The supervisors make improvements by observing and modeling during consultations with the pasantes, through systematic case discussion

FIGURE 1. Compañeros En Salud's global health and social medicine curriculum

GLOBAL HEALTH & SOCIAL MEDICINE MODULES

1 INTRODUCTION TO GLOBAL HEALTH AND SOCIAL MEDICINE (35 HOURS)

Offers a pedagogic proposal from a global health and social medicine perspective that allows health personnel to deliver services based on a thorough understanding of the context

2 CLINICAL INTERVENTIONS BASED ON DISEASE PREVENTION, TREATMENT, AND CONTROL (110 HOURS)

Enhances pasantes' clinical knowledge with evidence-based interventions that promote high-quality services at birthing homes and rural clinics

3 MANAGEMENT AND VALUES FOR DELIVERING CARE TO MARGINALIZED POPULATIONS (10 HOURS)

Promotes inter-professional participation that allows for the development of collaborative health care strategies linked to diverse community actors, as well as team-work abilities and compassion-based leadership

4 INTEGRATIVE WELLNESS AND RESILIENCE TOOLS (10 HOURS)

Offers tools that promote the development of intrapersonal and interpersonal skills for adapting to a complex context and building relationships harmoniously

for collaborative clinical decision-making, and by offering evidence-based treatments that reconcile with the traditional-medicine remedies and that are appropriate to the patient's particular reality. For example, supervisors teach obstetric-nursing students about childbirth care in the vertical position (squatting, sitting, or standing) and the use of the *rebozo* to facilitate labor, a "traditional midwifery practice of Aztec origin, which consists of using a scarf to perform different techniques in order to mobilize the pelvis and relax the muscles to favor the positioning of the fetus."[26] Obstetric-nursing pasantes also learn about the use of medicinal plants during pregnancy and labor and visit midwives in the region to exchange knowledge and ideas.

"Accompaniment" has been part of Partners In Health's operative framework since the organization began working in Haiti and Peru. Currently, Compañeros En Salud has endeavored to incorporate the accompaniment model into many processes, such as accompanying patients to visit community health workers, accompanying the Ministry of Health in its efforts to strengthen the health system, and through the supportive supervision model. According to Paul Farmer, co-founder of Partners In Health, accompaniment is defined as follows:

> To accompany someone is to go somewhere with him or her, to break bread together, to be present on a journey with a beginning and an end. There's an element of mystery, of openness, of trust, in accompaniment. The companion, the accompagnateur, says: "I'll go with you and support you on your journey wherever it leads; I'll share your fate for a while. And by 'a while,' I don't mean a little while." Accompaniment is about sticking with a task until it's deemed completed, not by the accompagnateur but by the person being accompanied.[27]

Pasantes receive oversight at the community rural clinics and at birthing centers, where their supervisors help them adapt to a new context, help them learn about the structural forces that make people get sick, and provide advice and manage expectations to allow pasantes to develop a structural competency lens of their own.

On-site supportive supervision for medical and nurse pasantes

At the community level, Compañeros En Salud provides comprehensive primary care for people living in or around any of the 10 communities with clinics that the organization supports along with the Ministry of Health. This care is provided through clinical teams that consist of a medical pasante, a nurse pasante, a graduated nurse, a health auxiliary, and community health workers. Each member of the team brings different skills to the table and provides distinct services so the clinics can deliver quality care to their users. A big part of the provision of quality services is an emphasis on training.

Such training is achieved by the continuous visits of clinical supervisors, registered nurses, and physicians with experience providing health services in rural areas, who spend a week every month in the communities in order to provide accompaniment, clinical mentorship, and management support to the clinical teams.

In some cases, supervisors also accompany pasantes during home visits to deliver medical care to where patients live. As mentioned earlier, this offers pasantes the opportunity to understand patients' living conditions, their daily dynamics, and the social challenges they face. The supervisor role promotes understanding of the social medicine concepts that are studied in the theoretical lectures, emphasizing "proximity" to people's context as a necessary element to convert the curriculum's learnings into experiential practices, which ultimately leads to providing better health care.

Clinical supervisors also reinforce the topics from modules 1–3 by either intentionally talking about subjects reviewed that particular month or by seizing teaching opportunities when clinically or socially complicated cases arrive at the clinics. Having someone with more experience to guide the clinical teams through such occasions represents a valuable opportunity for meaningful learning and professional growth. "Bedside teaching" is essential for all health professionals, as it allows for real-time feedback and for the practice of clinical skills in a controlled environment. Therefore, it is essential to have both the theoretical sessions in the monthly

training and the sessions of supportive supervision that help cement the acquired knowledge.

Supportive supervision for obstetric-nursing pasantes and midwifery pasantes

After a few years of working only with physicians, Compañeros En Salud expanded its operation to support a birthing center at the local hospital, Ángel Albino Corzo Hospital. This program was launched in collaboration with the National School of Obstetric Nursing and started receiving obstetric-nursing pasantes in 2016. The birthing center is one of the few places in Mexico where low-risk childbirth care is provided autonomously and independently by obstetric-nurses under the midwifery model. It is a place where midwifery and obstetric-nursing pasantes are trained in respectful, women-centered care. For instance, women's preferences around birth delivery position and family accompaniment are prioritized, in contrast to the unjust status quo of most birthing experiences in Mexico, where birth delivery is centered not on the woman's needs but on the needs of health personnel. Here, pasantes learn to guarantee the fulfillment of women's sexual and reproductive rights. As direct care providers, the pasantes provide consultations, counseling on sexual and reproductive health issues, delivery care, postpartum care, and immediate newborn care.[28]

During the supervision, nursing pasantes are able to put into practice what they learn through the GHSMC since they are accompanied at all times by five obstetric-nurse supervisors and a professional midwife who graduated from the program in a previous cohort. For example, in the course they review the term "social construction of reality," which shows that worldviews are built on ideas and practices determined by society, recognizing how people's behavior may be determined by their subjective construction of reality.[29] By recognizing that the woman, the traditional midwife, and they, as pasantes, have a different but equally valid perspective of a particular situation, they learn to establish a respectful, collaborative, and harmonious plan for all parties. This stands in contrast to the usual practice whereby providers impose their perspectives without listening to the patient's concerns or ideas.

Supervisors help nursing pasantes understand their patients' context through clinical assessments that inquire about where patients live in order to know the distance they need to travel to reach the services, what their support network is like, and what particular concerns might help adapt management to their context. Moreover, nursing pasantes are encouraged to incorporate local words into their language to facilitate more effective communication.

Pasantes spend 10 months working at the birthing center. In order for them to understand firsthand the context of the vast majority of women who seek care there, they live for one month in a small rural community where medical pasantes are based, strengthening the care and counseling provided to pregnant women or women of reproductive age in that locality. During this time, they also make home visits to accompany women in coordination with the primary care clinic.

Pasantes also spend one month at the second-level referral hospital where women who cannot be attended at the birthing center are transferred to. This large hospital's care is not centered on women's preferences. The pasantes' objectives at this site are to share the midwifery model of care and advocate for the rights of users.

Discussion

Since the 1970s, Latin American academics' discussions have challenged the mainstream ideas emanating from renowned universities in the Global North on social medicine.[30] For instance, by the 1970s, Argentinian physician César García had already started implementing community medicine, which would later evolve into social medicine.[31] And from the 1980s onward, global health associations such as the Latin American Social Medicine Association and the Latin American Alliance for Global Health were created in order to disseminate social medicine work and combat the neoliberal health vision, among other things; further, global health modules were included in university curricula in Chile, Brazil, and Peru.[32]

In Mexico, Compañeros En Salud's GHSMC

is one of the few global health or social medicine programs in existence. What makes Compañeros En Salud's approach unique is that it includes proximity to vulnerable populations and their social determinants of health.[33] It offers direct experiences of care and relies on the teaching-learning process, which is loaded with daily experiences that the pasantes observe, actively participate in, and reflect on under the guidance of mentors. It stands out for its affordability, as it has no cost for enrolled students; its appropriateness, as it is designed by and for health practitioners in rural Chiapas; its focus on practice rather than research, policy, or diplomacy; its holistic approach, as it combines theoretical lectures, case solving, and field practice with supervision under an enabling environment; and its alignment with the human rights framework, considering health as an integral human right that includes the components of availability, accessibility, acceptability, and quality. At its core is the concept of human dignity, why every human being deserves the highest level of medical care available, and why anything less than that is essentially unethical, particularly in a society that systemically assigns lower standards of care to the poor.

Therefore, the Compañeros En Salud curriculum not only teaches pasantes how to treat and follow up with patients but also provides the theoretical and practical tools to do so holistically. The approach would not be successful if pasantes

were solely placed in remote clinics with thorough instruction and supportive supervision but without medicine or equipment to solve the health demands in front of them. Indeed, being the only provider in a remote village without access to medicine is one of the main reasons why pasantes in Mexico experience frustration during their social service year. Although ensuring supplies is not a formal part of the curriculum, it provides the environment that allows the instruction component to become a reality. All of these aspects of Compañeros En Salud's educational model contrast with the traditional Mexican model, as summarized in Table 1.

The most outstanding outcome of this educational approach is that it can be transformational. Most of the current and past clinical management, nursing, obstetric-nursing, midwifery, and medical positions at Compañeros En Salud—including the organization's current director—have been occupied by former pasantes. Ex-pasantes have also occupied positions such as director of Ángel Albino Corzo Hospital, home to the birthing center and the COVID-19 ward operated by Compañeros En Salud. This challenges the logic that the "best" pasantes will inevitably run away from rural communities and are interested only in prestigious hospitals in large cities. It shows that people respond to being able to see and create change around them and that instruction can be inspirational.

Many ex-pasantes have pursued higher educa-

TABLE 1. Comparison between the Compañeros En Salud educational model and the traditional model

	Compañeros En Salud training curriculum	Normal training for pasantes
Classroom teaching	Monthly, regular, adapted to the real burden of disease; includes case presentations, role-plays and discussions of real-life situations	Irregular, sometimes only at the beginning, based on Ministry of Health programs and how to fill statistical and administrative forms that are reported to the Ministry
Bedside teaching	Weeklong, every month, includes clinic patients and home visits	Absent
Community engagement	Continuous, with an accompaniment model based on solid relations between Compañeros En Salud and communities	Usually only when the new pasante arrives at the community
Supervision and mentorship	Monthly, regular, based on problem solving	Irregular, usually only for administrative matters
Structural enablers	Guaranteed tools and medications	Frequent stockouts and lack of equipment

tion in global health and public health in renowned universities around the globe and have then come back to work at Compañeros En Salud. Others have pursued residency programs and worked in global health in Mexico and abroad, while others have continued to support the organization's activities, such as its surgical campaigns. And yet others have started their own projects in their respective institutions. As of 2019, there were 114 graduates of the Compañeros En Salud program. By the time of their graduation, 60% had applied to work at Compañeros En Salud, 48% had worked or were working at Compañeros En Salud, 49% were working in a field related to global health, 33% had completed or were doing a medical residency, and 16% had completed or were pursuing a postgraduate degree related to humanitarian work.

Most importantly, these graduates continue to serve the poor and pursue a relentless battle against injustice in health delivery and outcomes. In the words of ex-pasante Miguel Hernández:

> In the time I have spent at Partners In Health, I have begun to make the effort to listen before I speak. It is in the deepest silence that the voices of those we thought were silent begin to be heard. All that is needed is the will to pay attention to them and the courage to give them all that we can give.

Lessons learned

Providing a comprehensive curriculum designed to promote structural competency is not enough on its own. Theoretical knowledge without practical opportunities and support systems will always be insufficient to bring about real changes in care delivery. Accompanying the clinical teams has been crucial for applying the knowledge acquired in the classroom to daily practice. Adequate support systems and field supervision have been key to the success of this curriculum.

For professionals caring for rural and marginalized populations, structural competency in global health and social medicine should be integral to their training. We believe that the integration of such topics and the development of related skills should be an essential component of every program

that instructs physicians and nurses. It is vital that such training be recognized and embraced by leading teaching institutions so it has the necessary validity and recognition in academic settings, which will allow this subject to grow and permeate all of the structures of care delivery. Well-grounded alliances with universities to obtain certificates and continuing medical education credits would help encourage health professionals to pursue further education in these areas.

The most important challenge has been to design an interdisciplinary curriculum that provides clinical knowledge specific to the needs of each cohort while also encouraging multidisciplinary collaborative work in the clinical environment. We have observed that in order to foster a collaborative teaching environment, we must actively promote nursing, obstetric nursing, and midwifery leadership in clinical teams, thereby breaking down traditional hierarchies in the medical field. Moreover, a remaining question is how to build a training curriculum and supervisory support that adapt to pasantes' diverse needs and intra-and interpersonal skills.

In the future, Compañeros En Salud aspires to establish more proximity with the communities in order to understand their perspectives and, in turn, improve the services and care they receive. Last but not least, we have learned that the joint construction of a knowledge paradigm, agreed-upon intervention criteria, and the promotion of shared values between the medical team and the community generates the possibility of communicating through a language that helps unify the members of each cohort.

Conclusion

The impact of an education format that combines theory, practice, and the resources to link both falls into three domains. First, the social medicine approach is good for patients because it leads to better outcomes. Students are more aware of social barriers that influence patient behaviors such as missing an appointment or discontinuing a treatment course. They are able to understand the

contexts and lived experiences of the patients, their working and housing conditions, their family and social dynamics, and so forth. This improves their diagnostic capabilities and provides them with tools to improve patients' treatment completion, such as home visits.

Second, the model enables pasantes to do their job more effectively while reducing frustration originating from being alone and under-resourced in the face of difficult circumstances. It also creates spaces to promote community building with patients, colleagues, and supervisors.

Lastly, it is also good for organizations and society as a whole, as a comprehensive program such as this one can improve the retention of staff in rural areas, which is a problem even in high-income countries.

Compañeros En Salud is training multidisciplinary teams with the ability to understand and observe how health is not merely a biomedical issue but a complex social one that is specifically related to living conditions in the economic, environmental, cultural, and political spheres. This model expands the perspectives of students about what is possible regarding care provision in remote settings, which, in turn, helps these students become advocates to make health care a human rights reality.

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COMMENTARY

The Right to Health: Looking beyond Health Facilities

AGNES BINAGWAHO AND KEDEST MATHEWOS

In 1946, the Constitution of the World Health Organization first articulated the right to health, stating that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being."[1] This right was further enshrined as a human right in 1966 in article 12 of the International Covenant on Economic, Social and Cultural Rights, which communicates four core components—availability, accessibility, acceptability, and quality.[2] Furthermore, defining health as a human right insinuated the need for legal accountability, equality and nondiscrimination, and participation.

Even prior to the COVID-19 pandemic, states' commitment to the enjoyment of the highest attainable standard of health for all was unmet—at best, acknowledged—across the globe. The COVID-19 pandemic did two things. First, it undermined efforts to improve health outcomes and bridge gaps in health care delivery.[3] The interruption of health services, the rise in unemployment, and the increase in gender-based violence, to name a few indirect impacts, affected the most vulnerable.[4] Note, however, that this is not a novel realization—health crises have consistently affected the most vulnerable and have put accountability for the right to health on the back burner.

Second, and potentially one of the few silver linings of the pandemic, is the extent to which it has shone light on the necessity of enforcing the right to health and the fragility of human society in its absence. Failure to protect individuals' right to health has prolonged the pandemic and resulted in economic, social, and political chaos that has further thwarted efforts to achieve the former. The authors in this special section successfully highlight various ways in which stakeholders across the spectrum can work toward the enjoyment of the highest attainable standard of health. In this commentary, we draw from their expertise and our reflections on the right to health to discuss some strategies toward the fulfillment of this human right.

The achievement of the right to health requires patient accompaniment. Heidi Behforouz, ex-director of the Prevention and Access to Care and Treatment project at Partners In Health, describes accompaniment as follows: "Accompaniment in one sense is an easy term. You walk with the patient—not behind or in front of the patient—lending solidarity, a shoulder, a sounding board, a word of counsel or caution. Empowering not enabling."[5] Accompaniment was also highlighted by Paul Farmer, with whom we collaborated closely, and to whom this special section is dedicated. It extends beyond the delivery of quality,

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equitable health care services in health facilities and the physical accompaniment of patients to health facilities. The social, economic, and political conditions that enable individuals to access health services and maintain a healthy life must be put in place to facilitate the achievement of the highest attainable standard of health.

We can take the example of maternal and child health care to illustrate what expert patient accompaniment looks like. On the clinical side, this means holistic care provision to mothers and infants—quality antenatal care services, respectful facility-based delivery, timely postnatal care, and follow-up of the child, including the critical childhood vaccinations. Missing any step of the process will jeopardize the health of the mother or the child. But true accompaniment of patients goes beyond providing quality clinical services to addressing the social determinants of health. For instance, is the mother able to travel to the health clinic for all her antenatal care visits? Can the family afford the services for both the mother and the child? Do the mother and child have access to food and, more importantly, to a balanced diet?

Availing clinical services at health facilities is futile if patients cannot reach them or if patients are unable to keep themselves healthy due to lack of food. This is why accompaniment is critical; you address all the challenges that stand in the way of people achieving their maximum health potential. At the national level, the approach to health should shift from siloed clinical delivery to holistic maintenance of individual and population health. At the health-facility level, clinicians and managers need to be trained to identify these socioeconomic factors that prevent good health and connect patients to well-equipped resources that can address their concerns, as the framework of structural competency that is further developed in this special section emphasizes.

Training health professionals to practice medicine and lead health systems through such an equity lens requires the integration of social medicine into medical and global health curricula. Social medicine trains professionals to look beyond the bedside to understand and address social, economic, and political factors beyond the health care system that cause ill health or hinder access to health care services.[6] Students should not only learn about how the social determinants of health such as income can detrimentally impact health outcomes but also be able to think about all aspects of socioeconomic, cultural, and political well-being (the processes of social determination, as Jaime Breilh has argued), of which income is only one indicator.[7] Moreover, health professionals should also be equipped with the know-how to address these factors at all levels (intrapersonal, interpersonal, clinic, community, research, and policy).[8] This requires a mutlidisciplinary and inter-professional approach to medical and global health education, where one discipline or profession draws from others to collectively advance toward the fulfillment of the right to health.

This pedagogical approach must be accompanied by leadership, management, and communication training that will allow health care professionals to organize toward the attainment of the highest standard of health. At the same time, health professionals must be trained in structural humility: in not making assumptions about patients' lives, encouraging instead the ethical stance of collaboration with patients and communities in developing understanding of and responses to structural vulnerability.[9] Fresh graduates from medical schools sent to hospitals in remote, rural regions will often be expected to address governance, financial, and supply challenges in order to create a favorable environment for clinical care delivery. These are obstacles that hinder the achievement of the right to health; hence, health professionals must be equipped with these skills.

Critical to pushing these aforementioned strategies forward is community participation. Patient accompaniment is possible if the health system builds a trusted relationship with the community, allowing the community to openly discuss health challenges and the government to prescribe solutions that are acceptable.[10] Accountability to community demands and a commitment to the right to health build community trust in the public health system, which feeds back into improved

health outcomes, which, in turn, contributes to trust. Given that every nation-state has ratified at least one international human rights treaty recognizing the right to health, accountability mechanisms that break down this human right into clear actionable programs and policies and outlines consequences for non-adherence must be set up. This lack of specificity and clear consequences is a major reason for our stymied progress toward the attainment of the right to health—a right articulated in the World Health Organization's Constitution nearly eight decades ago.

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COMMENTARY

Global Voices for Global (Epistemic) Justice: Bringing to the Forefront Latin American Theoretical and Activist Contributions to the Pursuit of the Right to Health

PAOLA M. SESIA

The invitation by the *Health and Human Rights Journal* guest editors to provide a commentary for this special section comes just as we approach the first anniversary of Paul Farmer's untimely passing. As the date nears, I am inevitably reminded of, and deeply inspired by, Farmer's contributions and uncompromising commitment to global health equity, social justice, economic and social rights, and a rights-based approach in his clinical practice, intellectual work, and health activism.[1] In Farmer, such a commitment became particularly resolute in relation to the poor, the dispossessed, and the outcasts, wherever they may live: Siberian prisons; urban slums of Lima, Boston, or Port-au Prince; or poverty-stricken rural villages in Haiti, Peru, Malawi, Rwanda, Lesotho, Guatemala, or Mexico. Just as important among Farmer's legacies—and one that strikes a particularly sensitive chord with me, as a critical medical anthropologist myself—is the pursuit by this exceptional scholar of an activist, politically engaged, and nonetheless rigorous and reflexive medical anthropology.

The papers that make up this special section of *Health and Human Rights Journal* draw on some of these legacies and on other like-minded theoretical, practice-oriented, and activist frameworks, namely social medicine, collective health, and structural competency in medical, community, and public health training and service provision. The guest editors have envisioned the possibility of an enriching, cross-fertilizing dialogue between these three approaches and have encouraged a debate around their potentialities, without ever losing sight of the final goal: the fulfillment of the right to health for all. I surmise that the contributing editors clearly saw the potential of all three frameworks to expose and to dissect the impact of structural social inequalities on health and well-being, while also concretely promoting the right to health in actual practice.

The papers in this section take up the challenge to use one or more of these frames of reference to consider the right to health; they do so in different ways and to varying degrees, approaching them from different epistemic angles and applying them to diverse health problems in a wide range of socio-geograph-

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ical settings, including the United States, Chile, India, Uganda, Haiti, Spain, Mexico, Ghana, and Roma communities in Bulgaria, North Macedonia, and Romania. Most of the papers refer to the right to health or, more commonly, the difficulties or failure to fulfill it; some have engaged explicitly with the structural competency framework in service provision or in medical training, and others make explicit reference to the social medicine paradigm in their community and advocacy work involving the training of health professionals or the delivery of medical services. Two of the papers link to and draw from collective health and make contributions based on this framework in relation to the health, knowledge, and priorities of Indigenous people.

In my view, it is important to stress that two of these frameworks—social medicine and collective health—stand out as strong theoretical contributions from Latin America, a continent that has offered a particularly fertile ground for the development of original and innovative critical thinking in health and social sciences, as well as the promotion of the right to health as a basic human right in international law. I venture that the contribution from Latin America to the formulation and adoption of the right to health is probably unknown to most, for which reason I will dedicate a few lines in this commentary to that story as well.

It is with Farmer that I begin this commentary. My words are centered on the contributions of Latin American praxis-oriented critical thought in pursuit of health equity, social justice, and the fulfillment of the right to health as a basic human right—contributions that Farmer recognized in his own particular ways but that, by and large, tend to be ignored in hegemonic Anglophone global health production. This last point I find crucial, and I will pick it up again later.

As we all know, Farmer was stationed as a professor in the heart of privileged academia: the distinguished Harvard University, where much knowledge—including in social sciences, public health, clinical medicine, political economy, and critical theory at large—is created and from where much radiates to the rest of the world with the unmistakable imprint, distinction, and oftentimes

nonchalant obliviousness of its entitled origins. Far from being a pompous, convoluted, and conceited intellectual from the top of the top of hegemonic academia, Farmer was quite the opposite: people who knew him personally remark on his unpretentiousness, human and intellectual generosity, and deep-felt empathy with his fellow human beings and with the ever-expanding plights of deprived humanity.

We can also directly witness Farmer's writing, with his characteristic clarity of thought; his genuine expression of moral indignation at social injustices, human suffering, the unequal burden of preventable deaths, and "structural violence" experienced by the global poor; and his passionate defense of the underserved, marginalized, oppressed, exploited, excluded, and dispossessed individuals or social collectives from the Global South.[2] I would argue that his generosity, intellectual honesty, and humbleness also manifested themselves through an explicit recognition of the eclectic and pragmatic traditions of thought from which he drew inspiration, where some Latin American intellectual currents stood out. In many ways, inspired by these currents, Farmer proposed a broadening of our understanding of, and acting upon, health and human rights.[3]

Thus, Farmer openly declared how progressive Catholic liberation theology (especially with the figures of Archbishop Oscar Romero from El Salvador and Friar Gustavo Gutiérrez from Peru) and its focus on the poor, as well as Paulo Freire's pedagogy of the oppressed from Brazil, had a major impact on his ways of thinking and acting as a physician, medical anthropologist, and health activist, particularly his criticism of colonialism, capitalist exploitation, and neoliberal policies in global health and their adverse effects on the poor and dispossessed.[4]

To these, a third, perhaps less explicitly declared, vein came to make an impact on Farmer: a humanitarian strand of Latin American Marxist-influenced praxis where the development of critical thought has been inextricably accompanied and reinforced by a commitment to the transformation of unequal and unjust health conditions

and their underlying social causes. Undoubtedly, this progressive action-in-the-world-oriented praxis is present in both liberation theology and Freire's popular education.

Liberation theology and popular education also share a peculiar utopian drive in their uncompromising social engagement to transform unequal and oppressive conditions for the poor. I believe these features made both currents particularly attractive to someone like Farmer, who openly declared his aversion to detached, sterile, and speculative intellectual work that is too far removed from the daily struggle to make ends meet for most of the people of our living planet.[5] Farmer believed that knowledge is and should be produced first and foremost for social change in order to overcome injustice, inequality, and other prevailing social ills. It seems to me that his conviction was not solely the product of a rational mentalist intellectual exercise: it was *senti-pensante* (felt-thought), as Colombian sociologist Orlando Fals-Borda (the father of participatory action research) would say, and it was rooted in passion and moral outrage.[6]

Here, it is worth highlighting some parallels with these other Latin American critical currents of thought. In a similar way to Farmer's, Marxist-oriented praxis is a central tenet of Latin American critical epidemiology, social medicine, and collective health.[7] From the start, these three interrelated—at times, interchangeable—theoretical orientations have vehemently opposed what Farmer called "the public health orthodoxy" and have worked strongly for the right to health for all; and they have done so for decades, in many cases prior to Farmer.[8]

These theories have produced important studies on a wide variety of health and disease problems from a political economy perspective, revealing the complexities and entanglements of what Jaime Breilh calls the "social determination of health."[9] Influenced by Gramscian ideas around (1) the necessity to unite theory and action to mutually inform and reinforce each other, (2) the sociopolitical role of organic intellectuals, and (3) their direct engagement in conscious practice, proponents of these currents of thought have long posited that the

"generation and transmission of knowledge" are powerful "tool[s] for change."[10] I find it important to highlight these parallels and reflect on these theoretical orientations whose exponents have concomitantly promoted progressive health policies, social justice, and the universal right to health and health care. In Latin America, critical epidemiology, social medicine, and collective health (the preferential term for social medicine used in Brazil) have multiple identities, and their orientations are far from being monolithic. What is clear is that, all together and at the same time, they are thriving schools of critical thought, distinctive research fields and methodologies, and transformative social and political movements.

It is worth remembering that paradigmatic theories, especially those linked to transformative action, do not emerge in a vacuum; they may well flourish in very adverse circumstances, against dominant paradigms, and as counter-hegemonic projects. These frameworks are, in fact, the historical products of particularly challenging contexts: as we know, Latin America and the Caribbean are two of the most unequal regions in the world; nor should we forget that Farmer himself forged his thinking and life activism in Haiti, the poorest country of our entire Western hemisphere.

These inequalities are the tangible inheritance of a harsh history of colonialism, unfettered capital accumulation and predatory capitalism, centuries of pillage and devastation of nature across entire regions, the dispossession of Indigenous territories, the genocide of millions of Native and Black people, the brutal implementation of forced labor and African slavery in the plantation economies, and, after independence, the yoke of British and US imperialism. More recently, these inequalities have developed from the establishment of authoritarian regimes or outright bloody military dictatorships; the exercise of political violence and the massive or selective annihilation of the opponents to political or, increasingly, economic megaprojects; the predominant patriarchal *machismo* with its own culture of death; the ruthless implementation of structural adjustment programs and neoliberal doctrines; and the extreme concentration of power

and wealth among national economic elites. And most recently, inequalities are being worsened by the ongoing "war" on drugs and organized crime, with hundreds of thousands of people killed or disappeared. It may be worth (re)reading Eduardo Galeano's *Open Veins of Latin America* for a powerful, clearly articulated, historically informed, and morally outraged account of what the region has experienced from the conquest to the late 20th century.[11]

As schools of thought and research fields, critical epidemiology, social medicine, and collective health emerged or re-emerged in the 1970s in opposition to prevailing functionalist and positivist paradigms in hegemonic public health and preventive medicine at the time.[12] The conventional paradigms were ill-equipped to, and not particularly inclined to, understand the complexities and dynamics of social inequalities and health. Eric Carter and Marcelo Sánchez Delgado, for their part, maintain that the history of social medicine as a movement of ideas is not linear, coherent, or unidirectional; it does not respond to just one theoretical paradigm; and it distinguishes itself for being ideologically pluralistic and diverse, where—beyond contrasting postures within structural, historicist, or culturalist Marxian traditions—poststructuralist social theory, including Foucauldian and other ideas, have found fertile ground.[13]

Accepting the richness of this diversity, social medicine and collective health have developed critical intellectual traditions, particularly in Argentina, Brazil, Chile, Colombia, Cuba, Ecuador, and Mexico, at least since the 1970s but in some cases as early as the 1930s.[14] They have done so by promoting lively debates and building and consolidating collective associations and continental networks for the exchange of ideas, scholars, publications, and students. They have dedicated their reflections to the complex, dialectical, processual, and historically construed relationships between two aspects: on the one hand, health, the unequal burden of disease and mortality, social suffering, poorly financed care systems, and the expansion of medicalization to different spheres of human life, and, on the other, class structure and

inequalities, gender and ethnic subordination and discrimination, capitalism and colonialism, the extreme concentration of wealth and widespread poverty, racism, political violence, environmental destruction, dispossession, social deprivation, and the dissimilar formations and roles in health policies by nations-states and their state apparatuses, including the establishment of official medical institutions and public health care systems and the open or veiled support for the commodification and privatization of medical services.

One of the central theoretical propositions that critical epidemiology and Latin American social medicine have developed is the concept of "the social determination of health," an important analytical tool advanced by Breilh, a leading and prolific critical social thinker, physician, and epidemiologist from Ecuador.[15] Although not all agree with its epistemological premises, theoretical arguments, or possibilities of implementation, this conceptual approach has made an impact among many social medicine practitioners, academics, and schools in Spanish- and Portuguese-speaking circles of knowledge production and critical thought.[16] Breilh has been developing this concept since the late 1970s in order to stress the historical, material, ideological, dynamic, multicausal, and contextual nature of the "health, disease and care processes," a seminal concept coined by Eduardo Menéndez to which I return later.[17] Only very recently have some Anglophone practitioners, movements, and writers begun to explore, acknowledge, and utilize this concept.

The conceptualization of the "social determination of health" predates by several decades and presents important epistemic and ideological differences from the later and much more widely known formulation of "the social determinants of health" advanced by a commission appointed by the World Health Organization (WHO) in 2005.[18] WHO has been criticized for translating complex and dynamic social realities into discrete and isolated categories, organized in static hierarchies that do not allow full understanding of the underlying articulations and actual structural processes behind health and social inequalities.[19]

Some of the papers included in this collection refer precisely to this WHO notion, and Farmer himself referred to the social determinants of health as a welcome corrective to narrow biological theories of disease causation. As most other scholars from Anglophone academia or other non-Latin American latitudes, they are probably not familiar with the underlying debate, nor with the existence of this more precise, rigorous, processual, practice-oriented, and counter-hegemonic epistemic formulation. Only very recently is the social determination of health being brought to the English-speaking academy in a few major medical journals.[20]

One last major theoretical contribution to the contextual and dynamic understanding of health, health care, and medical pluralism in Latin America that deserves mention is the fruitful conceptualization of the "health/disease-illness/care process," "self-care," and "the hegemonic biomedical model" developed by Eduardo Menéndez, an influential medical anthropologist in the Spanish-speaking world who came from Argentina to Mexico to escape the military dictatorship.[21] Menéndez's contributions include a rigorous critique of public health policies, theoretical and methodological orientations, and limitations; his critique has been strongly inspired by Gramsci's historicist perspective and cultural hegemony theory.

Without losing sight of methodological and theoretical rigor in their analytical production, Latin American proponents of social medicine and collective health have actively participated in transformative social movements and political struggles, and many suffered the adverse consequences of their progressive political affiliations and their opposition to the military dictatorships of the 1960–1980s in the Southern Cone. Since the late 1970s, they have contributed to many important areas, including the development of progressive health and social policies in their respective national arenas; the struggle against structural adjustment and defunding of public health care systems; active opposition to the privatization and commodification of the provision of health services; the support of unions, worker, and grassroots organizations in their demands for better work, living, and environmental conditions; gender implications in the health/disease/care process; and the denunciation of malnutrition, infectious diseases, preventable child and maternal mortality, toxic waste and environmental pollution, and their differential impact on health status among disadvantaged social collectives. They have also promoted social accountability and community participation in health policies; the defense of social security funds; the inclusion of social sciences and critical thinking in medical and public health curricula; the formation of social medicine networks, associations, publications, and support groups across Latin America; mental health support to victims of torture and political repression; and the establishment of universal and free health care for all.[22] In particular, the establishment of health reform and the Unified Health System in Brazil at the end of the 1980s was to a great extent the result of the active participation of the *sanitarista* movement in the strong democratization drive that followed the end of the dictatorship; the Unified Health System has become a tangible contribution to the fulfillment of the right to health in this South American nation.[23]

Because the right to health constitutes an important unifying thread across the papers included in this special issue, I also want to mention the contribution of Latin American nations to the development of the right to health. Outside the circles of legal experts and historians of human rights, this is probably an unknown story to most people. Paolo Carozza and others have argued convincingly that the formulation of the right to health in international law drew heavily from a distinctive Latin American philosophy of human dignity, social justice, and the protection of perceived disadvantaged social collectives (such as mothers, children, and the elderly) that was influenced by a mix of socialist emancipatory thought, Catholic social doctrines of the late 1800s and early 1900s, and a new trend of 20th-century social liberalism.[24] This philosophy permeates most constitutions of Latin America, beginning with the 1917 Constitution of Mexico that was drafted after the Revolution and was an inspiration for other constitutions in the continent.[25]

Likewise, the integration of the right to health in the United Nations Universal Declaration of Human Rights of 1948 (and its subsequent inclusion in the International Covenant on Economic, Social and Cultural Rights, approved by the United Nations in 1966 during the Cold War) was also made possible by a series of favorable circumstances at the end of World War II in which Latin American nations played a key role. In 1945, 50 nations convened in San Francisco for the founding of the United Nations: 21 were from Latin America, the most sizeable regional representation of all.[26] Historians and legal scholars recall that the delegations from Chile, Panama, Cuba, Mexico, and the Dominican Republic were particularly vocal and worked in unison to champion the inclusion of economic and social rights—including the right to health—in the Universal Declaration of Human Rights, sharing a special concern for ethnic discrimination after the horrors of the Holocaust. In the end, it seems that it was the widespread knowledge of the atrocities committed by Nazi Germany and the urgent need for global peace (with the Cold War already looming) that finally overcame the reluctance of the United States, Great Britain, and France, who initially wanted to restrict the declaration to civil and political rights, primarily because their own constitutions did not include social and economic rights, which sounded too socialist in nature.[27]

This commentary on the multiple theoretical and programmatic contributions of Latin American scholars, activists, practitioners, policy makers, and even diplomats in furthering the right to health amounts to a deliberate and small subversive act in that it works against epistemic injustice in knowledge production and circulation.[28] Like the guest editors of this special section, I am convinced that these frameworks that originated in Latin American critical theory show tremendous vitality, theoretical strengths, pertinent methodologies, and analytical and transformative potential. They have produced in the past and continue to produce today significant, valuable, relevant, innovative, and vigorous evidence-based knowledge that better frames and reflects upon processes in which domination and subordination, economic exploitation and capital accumulation, dispossession and deprivation, patriarchy, and social discrimination and even extermination are historically enacted and reproduced along class, ethnic, gender, racial, age, national, cultural, and environmental lines. They also highlight how these multiple processes produce differential adverse effects on the health and well-being of specific individuals and collectives. In other words, I argue that these frameworks offer powerful epistemic tools to dissect, understand, and then potentially transform the dynamics around the functioning and unfolding of what Farmer called "structural violence," always contextualized in specific locations and times.

As a result, these frameworks deserve to be known to the large public health, critical social sciences, and human rights intellectual and activist communities around the globe. But the hard reality is that they are not. The generation of critical thought, policy achievements, or other transformative interventions in health from Latin America or from the Global South in general are immersed in an unwritten but very effective continuation of colonial relations in the political economy of knowledge production and distribution of our contemporary information era.

Latin American social medicine and collective health scholarship and its contributions to the generation of knowledge have been systematically obscured, largely ignored, and possibly even plainly erased in mainstream Anglophone global health literature and social health critical thought from the Global North. Examples abound. A first example is the widespread narrative among historians and public health specialists and practitioners in the Global North that centers almost exclusively on Rudolph Virchow from Prussia/Germany (and to a lesser extent Jules Guerin from France, or Edwin Chadwick from England) as the founding father of social medicine at a global scale, from which all subsequent developments in the discipline allegedly derived.

This is a historiographical metanarrative that arranges the spread of seminal socio-scientific ideas from Europe to the rest of the world in a neat, coherent, and linear continuity across continents and

times that cannot withstand an inquisitive gaze attentive to historical and contextual contingencies.[29] When all is said and done, it is profoundly Euro(ethno)centric and has become hegemonic in the literature; even Farmer, who traveled and came to know and appreciate intellectuals and activists from Latin America, usually referred only to Virchow as his motivating figure in his social medicine-inspired work trajectory.[30] Seemingly, this hegemonic metanarrative allows very little space for accounts that highlight vital and robust Latin American contributions to the field of social medicine. This special section of *Health and Human Rights Journal* is therefore an important—while of course initial, partial, and imperfect—attempt to counteract epistemic injustice based on colonial, ethno-nationalist, and racial capitalist relations.

A second example is provided by certain instantiations of the structural competency framework itself. In their seminal piece from 2014, Jonathan Metzl and Helena Hansen introduce this concept as if it were innovative and original to advocate for the need to teach structural competencies in clinical practice and to transform medical education in the United States. Succinctly, this proposal advocates for teaching critical thought to health personnel as a tool to change clinical interactions and the practice of medicine, to improve the understanding on the part of medical personnel of underlying social causes of ill health, and to envision possibilities of transformation of those social and health causes. I find that this proposal features striking similarities to previous recommendations made by Latin American social medicine scholars and activists since at least the 1960s–1970s with the implementation of some seminal teaching programs for health professionals in Mexico and Brazil. These teaching programs were actively and financially supported by individuals such as Argentine physician and sociologist Juan César García, who worked at the Pan American Health Organization from 1966 to 1984.[31] The Mexico teaching program continues today and has trained several generations of health professionals in the "structural competencies" that the social medicine framework provides. Metzl and Hansen's article makes no mention of this preceding

experience; likely, the authors had never heard of it, although it was reported in several publications in Spanish and English.[32] The point I want to make is that while this social medicine experience from Latin America is mostly unknown and rarely cited in mainstream Anglophone academic journals, the structural competency framework proposed by Metzl and Hansen enjoys recognition, and their article is cited globally. This special section of *Health and Human Rights Journal* is a rare example of acknowledgment of the contributions from Latin American social medicine and collective health by scholars involved in structural competency and other frameworks in the Anglophone world.[33]

A third and final example is the erasure of Breilh's "social determination of health" concept from mainstream Anglophone public health, critical health and social sciences, and epidemiology journals. In an all-too-often repeated history in Anglo academic-scientific production and circulation, the alternative formulation of "the social determinants of health" was published much later in English and disseminated globally in highly rated and often-cited journals and in working documents from key multilateral agencies. It quickly became hegemonic in global health, with no mention of Breilh's concept, although Breilh himself argues that many of the experts in the WHO commission who came up with the "social determinants of health" idea were familiar with his work and knew of its relevance.[34] If this is true, this double process of expropriating concepts without acknowledging their intellectual origins and presenting reformulations of them as original ideas amounts to an act of intellectual extractivism, made possible by prevailing colonial relations in knowledge production and circulation between "core" and "peripheral" academia.[35] Breilh's recent book-length publication in English and his forthcoming article in *Global Public Health*, as well as commentaries on his work in English, may just begin to help counteract this trend.[36]

The systematic exclusion of contributions from Latin American as well as other non-English-speaking "peripheral" schools of critical thought from the hegemonic circles of knowledge production and

circulation in the Global North has been exposed by several scholars throughout the years.[37] In relation to this problem, I turn to my last comment. The exclusion cannot be explained entirely or solely based on the existence of language barriers, since there have been some concerted efforts to publish and make available to audiences of the English-speaking world literature from the social medicine, collective health, and critical epidemiology frameworks, originally published in Spanish or Portuguese, and to reconstruct in English publications the historical genealogy and contributions of this field of critical thought. To make my point, it suffices to scan some of the sources referenced in this essay, several of which have been published in English—and some even in leading public health journals.

Colleagues and I have made similar arguments with regard to critical medical anthropology produced in Latin America—arguments that can be easily applied to the field of social medicine and collective health. We reflected on some of the explanations forwarded by important critical thinkers who are sensitive to this issue, explanations that I recall here:

> *Waitzkin et al. (2001: 315) suggest that this lack of impact [of Latin American academic production on health and social sciences] "reflects an erroneous assumption" that the "intellectual and scientific productivity of the 'third world' manifest a less rigorous and relevant approach to the important questions of our age." Narotzky (2002) points out that hegemonic Anglo-American academia has systematically ignored anthropological production published in Spanish, including by those who work from similar political economy perspectives. Martínez Hernáez (2008) … argues that there are multiple ironies to this obliteration. This includes Anglo-American anthropologies' and Critical Medical Anthropology's claim to ownership of political economy and neo-Marxist theoretical approaches that originated in Latin American critical thought (such as dependency or under-development theories) or in southern Europe (Gramsci's theory of hegemony), while they ignore social science production that builds upon these traditions in Portuguese, Spanish or Italian. Other progressive theories such as collective health and social medicine have been marginalized and colonized, while the epistemic hierarchy of*

> *scientific knowledge production and the hegemony of the anglophone academic systems of ranking and qualification remain unchallenged (Santos 2014).[38]*

In reference to medical anthropology, Martínez-Hernáez conjectures that the invisibility in hegemonic Anglophone academia of critical thought generated in peripheral regions such as Latin America is the result of a peculiar form of ethnocentric intellectual domination (I would call it "intellectual colonialism") that posits that all knowledge produced and circulated in languages other than English or external to self-established Anglo intellectual frontiers is inconsequential and therefore does not deserve any attention.[39] He also ventures that Anglo and Anglo-influenced academic scholarship is immersed in an accelerating process of commodification that requires continuous theoretical innovations to increase what I would call its exchangeable value in the global market of knowledge production and consumption. Menéndez makes a similar point on the need to innovate theoretically when he discusses the constant inventions and obliterations of concepts in the history of social and medical anthropology, including in Latin America.[40] I clarify that commodification is not just an economic process; it also and primarily involves cultural capital attached to varying degrees of academic prestige. In the end, these two concomitant processes identified by Martínez-Hernáez go a long way in explaining why Latin American social medicine and collective health are largely unknown or ignored in hegemonic Anglo public health and social science literature (including literature produced from a critical emancipatory perspective), while the structural competency framework, generated much more recently in US academia, is beginning to enjoy wide global audiences.

I will not go further in this critique regarding the political economy of knowledge production, circulation, and consumption because it would go beyond the scope of this commentary. I want to clarify that I have no intention of marking a clear-cut categorical distinction between critical thought produced in the Global South versus critical thought produced in the hegemonic academy of the Global North. In the real world, these processes are much

more complex, confused, multidirectional, and contradictory. Nor am I interested in constructing a counter-hegemonic grand metanarrative apologetic of Latin American critical thought in health and social sciences. What I propose is the inclusion of a serious and transformative discussion on epistemic justice in our debates around the cross-fertilization of critical thought paradigms in global health and social sciences. And, in the best tradition of Marxist-inspired praxis and following the legacy of Paul Farmer, I am looking forward to actively and collectively subverting the hegemonic rules of a commodified and colonial science. In this endeavor, we should always keep in mind that the ultimate objective is to construe and use knowledge in order to make the world a better place, foster human solidarity, struggle for social justice, achieve well-being, and make the right to health true for all. Only collectively can we strive in that direction.

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40.   E. L. Menéndez, *La parte negada de la cultura: relativismo, diferencias y racismo.* (Barcelona: Bellaterra, 2002).