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Editorial

Bioethics and the Right to Health: Advancing a Complementary Agenda

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This special section in *Health and Human Rights Journal* explores the relationship between bioethics and the right to health. Although bioethics scholars may argue for a right to health, particularly in the domains of universal health coverage and global health governance, and human rights scholars may advance ethical norms in their work, there has been little scholarly attention to the intersections, synergies, and contrasts between these two areas of study. At first glance, this is surprising given that bioethics and human rights share conceptual and normative terrain in articulating guidance for action on health-related issues, and international policy and practice is explicitly interrelating human rights and ethics.[1]

Bioethics is an interdisciplinary field with theoretical roots in medicine, public health, philosophy, and law. It is particularly well-developed in relation to ethical issues of health care and health research and to the duties and obligations owed to particular individuals, such as patients and research participants.

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Over the last decade, however, the scholarly focus of bioethics has increasingly embraced population and public health considerations.[2] This focus has seen the elucidation of norms to guide health-related actions within and across health systems, including the social, structural, and transnational determinants of health. These foci overlap with international human rights law in its recognition of the right to the highest attainable standard of physical and mental health—that is, the right to health.

Since 1946, the right to health has been recognized as a fundamental human right in international and regional instruments and national constitutions, creating entitlements and duties in relation to accessible and adequate health care and the underlying determinants of health.[3] Hence, one might expect that bioethics and international human rights would be engaged synergistically at a conceptual and practical level to tackle complex health challenges. However, our observation, through prior scholarship and the process of advancing this special section to publication, is that synergistic engagement has been the exception rather than the rule.[4]

In this special section, we set out to understand this lacuna and to explore where there might be opportunities for greater synergy to advance better health for all. We invited contributions exploring the relationship between bioethics and the right to health, particularly related to:

- the conceptual and theoretical underpinnings of a right to health from different normative perspectives within bioethics (for example, law, philosophy, public health, medicine);
- the degree of concordance or discordance between bioethics and international human rights law conceptions of the right to health, and the implications of this concordance/discordance for health policy and/or practice;
- the potential contribution of bioethics as a field to addressing challenges in implementing human rights frameworks (for example, deciding whose rights ought to have priority in cases of competing rights-based claims);
- the potential contribution of international human rights as a field to addressing challenges in implementing bioethics frameworks (for example, establishing institutional accountability for action); and
- the potential contributions of a combined bioethics and human rights approach to addressing complex challenges of health and health equity, such as global health governance, universal health coverage, sustainable development, or health system transformation.

The papers in this special section cover much of this ground. Together, they map out diverse health-related issues where bioethics and human rights intersect at individual and population health levels in relation to clinical trials, public health emergencies, maternal health care, early childhood development, epidemics, and priority-setting of health resources. We believe that the papers illuminate three particular approaches to the intersection of bioethics and human rights: (1) how bioethics could strengthen human rights approaches to the right to health; (2) how human rights approaches to the right to health could strengthen bioethics; and (3) how an integrated approach might better advance the right to health—locally and globally—in health care, health research, and health policy. Below, we summarize key insights from this collection of papers.

Bioethics as a means of strengthening the right to health

The starting point for Audrey Chapman's paper is the justificatory foundation for a right to health based in *dignity*. Although dignity is commonly referenced in international human rights instruments, the term is neither conceptualized nor explicitly translated into specific rights, including health. Chapman contends that this lack of explicit justification of dignity as the foundation of the right to health has contributed to a lack of consensus on this right's content, scope, and requirements; judicial interpretation; and application to priority-setting of health resources. Chapman proposes that Norman Daniels' theory of just health offers a promising justificatory framework for the right to health based on societal obligations to ensure fair equality of opportunity (FEO), which includes conditions that promote health as a critical enabler of FEO. Chapman argues that Daniels' approach to health justice, which exemplifies the groundbreaking contributions of political philosophy to complex ethical challenges of limited health resources, strengthens the case for a right to health by providing a strong rationale for the moral importance of health, health-related institutions and services, and the social determinants of health.

In their commentary, Diego Silva and Maxwell Smith appeal to the bioethical principle of *reciprocity* to augment analysis of and to legitimize restrictions of rights under the Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights.[5] Using the Ebola outbreak as an example, they point to the potential long-term disadvantage to individuals and communities resulting from restrictive measures and the potential implications this may have for the willingness of individuals and communities to comply with such restrictions. Silva and Smith argue that the principle of reciprocity provides a justificatory basis for such restrictions. In addition, reciprocity establishes a positive duty on governments to provide individuals burdened by restrictive measures (such as isolation and quarantine) with resources they require in order to comply with these measures (such as food and water).

Jerome Singh explores how bioethics can complement the right to health in realizing ongoing access for clinical trial participants to pre-exposure (PrEP) drugs to prevent HIV in South Africa. In South Africa, the constitutional right to access health care services has been credited with triggering vastly enhanced access to antiretroviral drugs for HIV treatment and prevention of mother-to-child-transmission. However, despite licensure in other jurisdictions and clinical trial evidence of effectiveness, the South African government has yet to extend the constitutional right by licensing access to PrEP drugs such as Truvada. Singh describes how bioethics norms are ensuring that eligible individuals in PrEP trials maintain post-trial access to PrEP drugs and are therefore playing an important complementary role to human rights norms in realizing the right to health for trial participants in South Africa.

Right to health as a means of strengthening bioethics

Fatma E. Marouf and Bryn S. Esplin's paper addresses a long-standing bioethics debate about the appropriate standard of care for clinical trials. The Declaration of Helsinki provides ethical principles for medical research involving human participants that require researchers to test new interventions against the best-proven intervention.[6] However, the Declaration is unclear on whether this means the best intervention worldwide or locally. In low- or middle-income countries, a local standard of care might mean no care at all, or care at a level below the global best standard. Marouf and Esplin argue that a minimum standard of care should be set for clinical trials and that international human rights provides the basis upon which such non-derogable obligations might be defined, justified, and executed. Marouf and Esplin suggest that minimum core obligations could define a middle ground that recognizes the practical challenges of providing a global best standard of care in all health systems while setting a minimum standard of care for all control groups globally. However, as Marouf and Esplin note, the human rights field has been slow to address this issue: "[the] real surprise is how little human rights bodies have thus far engaged dilemmas in clinical research aside from informed consent." Hence, their paper is a call to those working in bioethics and human rights to address this issue of global health equity in clinical trial research.

Contributions toward an integrated bioethics and human rights approach

The special section includes two papers that affirm that bioethics and human rights are not merely complementary—correcting for limitations in each approach—but constitutive of a novel approach to advancing the right to health. Avram Denburg investigates the complex example of health policy for early childhood development (ECD) in an evolving scientific context where genetic and epigenetic evidence is contested. From his perspective as a pediatrician, Denburg sees considerable synergies between human rights and bioethics that can be illuminated through application to specific domains of health policy. Denburg argues that ECD is an area of science and policy that exemplifies the power of a combined approach, since bioethics (particularly its arm of critical public health ethics) can help inform responses to inequality. He proposes that the capabilities approach:

> [focuses] moral attention on ECD as a substantive and irreducible capability for human development … [that] offers justification for the promotion of child health and wellbeing that is qualitatively distinct from adult health.

In contrast, human rights focus on those most in need of protection, giving primary attention "to protection from harm where damage would be greatest." This includes training a lens on children, who are dependent on others to promote their well-being, and thereby emphasizing the importance of children's rights. Denburg suggests that findings from epigenetic research provide fertile ground for examining synergies between bioethics and human rights. He cites studies showing that parenting induces lasting changes to infant brain development and behavior, including in relation to increases in neuropsychiatric; endocrine; and cardiovascular disease, with some of these changes becoming heritable. He argues that these findings indicate that the locus of normative policy analysis in ECD must shift to parental biology and circumstance, and that bioethics and human rights offer mutually reinforcing arguments for collective and socially embedded conceptions of justice in child health and development that enhance capacity for normative policy analysis in relation to evolving epigenetic knowledge.

In another commentary, Joanna Erdman argues that both bioethics and human rights approaches to the right to health must necessarily be attentive to lived experience, institutional culture, and structural injustice. Her sociological critique of bioethics and human rights is motivated by concerns about the documented ill-treatment of women in maternal health facilities globally.[7] Although such practices are abhorrent to both bioethicists and human rights scholars and practitioners, Erdman contends that any meaningful change requires moving beyond defining and applying ethical principles to prevent disrespectful and unsafe maternal care toward a robust system of rights that extends to the operation of health institutions and systems. Erdman argues that the sociological critique of bioethics—and by extension, of human rights—reconstructs the enterprise of ethical analysis "by enlarging the sites of inquiry, the categories of analysis, and the strategies of intervention." In doing so, she argues, a sociological approach to bioethics and human rights would offer a way for global maternal rights advocates to work towards transformative social change in the intimate spaces of patient care.

Bioethics and human rights: A synergistic future to improve health

The papers in this special section illustrate how complementarities between bioethics and human rights have the potential to advance health in a variety of domains, with a synergistic approach promising a whole greater than the sum of its parts. We found that most submissions to the initial call for papers focused on the contribution of bioethics to the right to health (rather than vice versa). On the one hand, this may reflect the interdisciplinarity of bioethics scholarship, which draws on both ethical and legal elements in its analysis. On the other hand, it may reflect a dearth of bioethical training within legal education, suggesting a curricular gap in the context of health and human rights law. In this light, these papers offer much-needed new scholarship in this field.

However, much opportunity remains for understanding the unique and constructive integrated contributions of bioethics and human rights for advancing health and addressing—and redressing—conditions that threaten well-being. The imperative to advance a synergistic approach to bioethics and human rights is even greater in the emerging global health context, where there is great need to find common ground among legal scholars, advocates, ethicists, health practitioners, and policymakers in addressing the health needs of individuals and populations.

As co-editors of this special section, we extend our gratitude to everyone who submitted to this call to advance knowledge and thought in a critical normative area of health. We are encouraged that scholars from such diverse contexts would find that the theme of bioethics and the right to health resonates with their work. We are gratified that the submitted papers identified so many practical issues at the interface of bioethics and the right to health and elucidated novel duties and justifications for action in this regard. It is our hope that this special section motivates ongoing and in-depth scholarship and practice in this domain.

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