

Article

Struggles for Human Rights in Health in an Age of Neoliberalism: From Civil Disobedience to Epistemic Disobedience

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Abstract

Like other contributors to this special issue and beyond, I believe we are at a critical inflection point in human rights and need to re-energize our work broadly to address growing economic inequality as well as inequalities based on different axes of identity. In relation to the constellation of fields involved in ‘health and human rights’ specifically—which link distinct communities with dissonant values, methods and orthodoxies—I argue that we also need to challenge ideas that are taken for granted in the fields that we are trying to transform. After setting out a personal and subjective account of why human rights-based approaches (HRBAs) are unlikely to be meaningful tools for social change as they are now generally being deployed, I suggest we collectively—scholars, practitioners and advocates—need to grapple with how to think about: (1) biomedicine in relation to the social as well as biological nature of health and well-being; and (2) conventional public health in relation to the social construction of health within and across borders and health systems. In each case, I suggest that challenging accepted truths in different disciplines, and in turn in the political economy of global health, have dramatic implications for not just theory but informing different strategies for advancing health (and social) justice through rights in practice.

Keywords: biomedical paradigm; human rights-based approach to health; neoliberalism; political economy; right to health; Sustainable Development Goals

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1. Introduction

As Philip Alston suggested in these pages in 2017, human rights have always been—and always will be—a struggle (Alston 2017: 3). There is no finish line to cross; using rights for social change is inherently iterative, which is both a weakness and a strength—because the process matters. Nonetheless, there is no denying that we are at a critical inflection point in the human rights movement. We face a crisis of legitimacy in popular adherence to basic democratic principles as well as the utility of the post-World War II human rights enterprise. Critiques come not just from conservative nationalists and populist autocrats, but also progressives who argue that the human rights movement has been either complicit in the rise of neoliberalism, or ‘a powerless companion’ ineffectual at constraining its devastating consequences (Klein 2007: 147; Moyn 2018: 176–80).

While many of these critiques paint ‘the human rights community’ with an overly broad brush and little nuance, we who consider ourselves part of the tapestry of that diverse global community do need to grapple with the failures of our tools and strategies to promote greater egalitarianism, and to move beyond sufficiency, in health and beyond. When Samuel Moyn suggests that the human rights community needs to ‘engage in open dissidence against [neoliberalism] or, at the very least, connive with others who break into open rebellion’ (Moyn 2018: 216–7), I agree. After all, by 2015, the wealthiest one per cent had accumulated more wealth than the entire rest of the world population (Hardoon et al. 2016), and the concentration of private privilege and power forged and sustained by a neoliberal political economy simply cannot coexist with the vision in the Universal Declaration of Human Rights, in which ‘everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized’, including the right to health (Article 28).

Far from ‘operationalization’ of human rights, including through global health governance institutions (Meier and Onzivu 2014), I believe we are in a struggle for the soul of the idea of human rights as it relates to health, and beyond. Open dissidence in the face of neoliberalism calls for more civil disobedience and direct action, and less bureaucratic ‘mainstreaming’. But, over the past two decades, some within the field have argued continually that combining health and human rights in meaningful ways also requires thinking differently—epistemic disobedience—not just in law but in both fields to reveal and dismantle the synergies that prop up unjust power structures, including a political economy dominated by neoliberal assumptions about the primacy of markets over the state (Yamin 1997; Farmer 2004; Chapman 2016).

This journal is dedicated to human rights practice, and the development of human rights-based approaches to health (HRBAs) in the 2000s was an attempt to build bridges of practice between fields with different methods, different goals and different epistemologies. Nevertheless, the way HRBAs generally have been designed and deployed too often reproduces the epistemic and institutional power structures within each field, rather than exposing and subverting them. Thus, after sharing subjective reflections on how we got where we are, I argue that applying human rights to health requires destabilizing the depoliticized ways of framing the world that stem from disciplinary orthodoxies in medicine and public health. In health, it is imperative but insufficient to think about human rights law in new ways; medicine and public health also need to be interrogated. The health sciences are often taken as technical or accessible to specialized expertise, but the frameworks in which they operate interact with neoliberalism and deeply affect our lived realities. First, I discuss the implications of understanding biomedicine in relation to the social as well as biological nature of health and well-being in a rights framework. Then, I turn to examine

conventional public health in relation to the social construction of health within and across borders, and in increasingly privatized health systems. Each of these topics has been the subject of significant academic writing. But the point of this article, in this issue, in this journal is that we collectively need to face these challenges if human rights practice is to remain relevant to struggles for greater health and social justice.

2. How did we get here? The evolution of efforts to apply human rights to health

In the late 1990s and around the turn of the millennium, in the afterglow of the adoption of a wave of new ‘transformational’ constitutions that set out social rights, including health, aspirational development conferences at the UN that elevated human rights in global discourse, and the establishment of UN special procedures around social rights, interlinked communities began to extend the relationship between human rights and health. In moving beyond autonomy, non-discrimination and civil rights protections, a principal goal was to establish that health effects of growing neoliberal development and other policies were not merely unfortunate externalities, but could be categorized and enforced as legal rights violations (Forman 2008). The most famous example is that of HIV, where after a proven therapy was announced at the annual AIDS Conference in 1996, activists around the world and perhaps most famously in South Africa took the government to court to force the provision of Prevention of Mother to Child Transmission (PMTCT) and other therapies (*Minister of Health v. Treatment Action Campaign* (2002)). While the use of litigation may be the best known part of the HIV/AIDS story, the use of the courts was embedded in broader social struggles, which had a goal of opening up political space. This was true not only in post-apartheid South Africa where understanding of the politics of the street was well-entrenched in a generation of activists (Forbath 2010), it was also true around the world, as networks of activists bridged North and South, scientific, cultural and legal communities to challenge the idea of intellectual property rights over health, among other things.

At the time, it was absolutely essential to demonstrate that in responding to health issues such as HIV and maternal mortality (where a similar paradigm change had occurred regarding emergency obstetric care) states were obligated to take ‘appropriate measures’, as a matter of *opinio juris*, not largesse. What was normatively required is inherently linked to what we know from best evidence in science and public health, which in turn can undergo profound revolutions in paradigms when normative conceptions shift. Thus, we recognized early on that following the best current evidence *alone* was not enough to achieve transformative results in policy.

It was necessary to demonstrate how applying human rights to health would imply both thinking and also acting differently from conventional public health and development approaches, from policymaking to implementation of programmes. As UN Secretary-General, Kofi Annan had called for mainstreaming human rights throughout the UN, but it was Mary Robinson’s appointment as UN High Commissioner for Human Rights that in practice advanced the notion of developing a rights-based approach to development. In 2003 the UN set out a ‘common understanding to a human-rights based approach to development’, which called for development assistance to be based upon and promote human rights principles including universality and inalienability; indivisibility; interdependence and inter-relatedness; non-discrimination and equality; participation and inclusion; and accountability and the rule of law (UN Development Group 2003).

It is important to note that in the early 2000s, the global development paradigm had shifted dramatically away from the broad trans-sectoral understanding of human development in the UN conferences of the 1990s to the technocratic agenda of the Millennium Development Goals (MDGs). Health was prominent in the MDGs, occupying three of eight Goals, and relating to almost all of them. Nevertheless, the top-down, siloed approach to development was clearly at odds with an approach based on human rights, which focused on legal and institutional change as well as technical interventions.

For many of us, one driving factor in the development of HRBAs was that the disease-specific approach in the MDGs was so obviously inappropriate for understanding health from the perspective of human beings who have life plans, and may transit through or suffer from multiple health conditions which affect their ability to carry out those life projects. Take the vivid example of Salome Karwah, the Liberian nursing assistant named a *Time* ‘Person of the Year’ in 2014 for her valiant struggle against Ebola in that country. Karwah lost her parents, aunts and uncles, but somehow survived, as did her fiancé. Yet, in February 2017, Salome died in childbirth because of a failed health system, stigma, and the same social determinants of health that put people at risk of death from multiple causes, which had not been addressed (Baker 2017). Thus, the first intergovernmentally approved understanding of an HRBA adopted through a resolution of the UN Human Rights Council emphasized that an HRBA was about empowerment of people with respect to their lives—not just access to services, important as they are—and attempted to set out ‘the application of *the* human-rights based approach’ [emphasis added] in the context of maternal health, but as the text specifically clarified, an HRBA was not about isolated pathologies (UN Human Rights Council 2012: para. 13).

Since then, HRBAs have proliferated, setting out some common principles such as the inclusion of analysis regarding legal and policy frameworks; the importance of multi-sectoral and participatory planning and budgeting; effective programme implementation; monitoring and evaluation designed to capture disparities/discrimination; and ‘accountability’. Despite this common framework HRBAs have set out widely varying understandings of the content of fundamental principles including accountability, the demands of meaningful participation, and the implications of formal and substantive equality in practice. In my view, the most transformative efforts to use HRBAs have been organic, focusing on people’s appropriation of their agency and collectively making changes in communities and institutions (Dasgupta et al. 2015; Samuel and Frisancho 2015; Polet et al. 2015). With notable and important exceptions, such as work by the Scottish National Human Rights Commission, the tendency from Human Rights Officialdom has too often been to push to ‘operationalize’ HRBAs in ways that may respond more to donor or governmental demands than ground-level social change. On the one hand, this is done by ‘demystifying’ the legal language of human rights for national-level policymakers, programmers and the like, and supporting selective civil society engagement. On the other hand, there are a plethora of efforts to ‘mainstream’ human rights in global health institutions, such as the World Health Organization (WHO), the Global Fund to Fight AIDS, Tuberculosis and Malaria, and UNAIDS (Magar et al. 2019). The current WHO Director-General has described the ‘mainstreaming’ process as having the aspiration that ‘each WHO staff member has the core value of gender, equity and human rights in his DNA’ (Meier and Gostin 2018: 10). That is no doubt a laudable goal, and some in the field see the future of health-related rights as operationalization through global health governance (Meier and Gostin 2018).

Of course it is important to be attentive to the way global health institutions are structured and use human rights in their work. Indeed we should all be concerned about the role of health governance institutions in fostering global health justice when, among other things, Peter Sands, the Director of the Global Fund, argues in a *Fortune* magazine op-ed that ‘the global health community needs to ask itself why it has failed to engage the private sector successfully’ (Jha and Sands 2019). Sands’ plea is actually indicative of the change he is touting. Nonetheless, in 2019, it is not plausible that activities to ‘mainstream’ or ‘operationalize’ rights, performed against the backdrop of increasing corporate and philanthro-capitalist influence over current institutions of global health governance and the permeation of neoliberalism into global health and development generally, can transform the structural conditions that immiserate and sicken swathes of people across the globe (Chapman 2016).

From the beginning, the paradox of trying to use powerful institutions to diffuse political as well as economic power in health through the inherently conservative tools that legal rights provide was not lost on many of us within human rights. For example, in a 2014 article in this journal, Rebecca Cantor and I concluded that if HRBAs ‘are to present a meaningful alternative to conventional public health and development approaches’ they centrally need to grapple with the loci and dynamics of power in specific contexts, and at the international level (Yamin and Cantor 2014: 477). In retrospect, the problem is not just that HRBAs have too often attempted to strip away the inherently political and contested nature of rights struggles (ibid: 454). That is a symptom of deeper problems in the practice of applying human rights in relation to health, which include the use of human rights law in ways that often reinforce rather than challenge larger governance models (Kapczynski 2019). However, they also include a lack of critical reflection on the underlying premises in the fields of medicine and public health.

3. Critical approaches to biomedicine

3.1 The power to define normality and deviance

The application of human rights in health has an ambivalent relationship with biomedicine because on the one hand, as noted, we depend on science to define appropriateness of measures and dispel demonstrably false ideas (for example, HIV does not cause AIDS; climate change and, in turn, its health consequences are unrelated to human activity; vaccines cause autism; or obstetric complications can be prevented and predicted across populations). On the other hand, the view from science is not a view from nowhere; like all frameworks for understanding the world, throughout modern history (and still today) biomedicine has been used to categorize, regulate and control human beings (Foucault 1973). The WHO Constitution states that ‘health is a complete state of physical, mental and social well-being, and not merely the absence of disease’ (WHO 1946: Preamble, para. 1). That utopian definition is a weak starting point for practical rights advocacy in many countries.

Nonetheless, the WHO definition was and remains critically important for the way we think, and in rejecting the way health is construed in biomedicine as the absence of disease or pathology—or, stated positively, ‘species-normal functioning’ (Borowy 2014: 517–8). Yet, despite the rhetoric of the WHO Constitution’s preamble, the biomedical understanding of health has become so entrenched in both research and training of health professionals, global and national health institutions, and public discourse in the West, that its premises and implications are taken for granted. Once a frame for understanding the world becomes so normalized, its influence on the structuring of institutions and behaviour

becomes obscure. Indeed, the technical language of scientific ‘expertise’ cloaks the deeper political implications of decisions in biomedical research and clinical practice, which encode narratives of how we understand social beings as human bodies, and of sexuality, (dis)abilities, race, and the like.

3.2 Why does this matter for human rights practice in relation to health?

The campaign by sexual and reproductive health rights (SRHR) activists in Latin America for the legal recognition of ‘obstetric violence’ provides an excellent example. ‘Obstetric violence’ explicitly goes beyond the WHO terminology, which is regarding ‘disrespect and abuse’ of pregnant women. Disrespect and abuse refer to the abuse of power involved in physical or emotional mistreatment, where important cases have been brought in the courts, including in Kenya (Odallo et al. 2018; Center for Reproductive Rights 2018). However, typifying ‘obstetric violence’ goes further; it challenges the pathologization of natural reproductive processes, and in turn the very different kind of power biomedicine exerts in defining what is happening in our bodies.¹ In turn, it is important that ‘obstetric violence’ legislation and advocacy call for different forms of education and prevention—which go to these epistemic issues—and not merely punitive sanctions on individual providers (Vacaflor 2016).

‘Obstetric violence’ is a relatively ‘easy case’ because biomedicine is interacting with patriarchy to interfere directly with our life projects as women, literally forcing our bodies into certain positions to ease the work of the physician-subject of the process (Malacrida and Boulton 2014; Martin 2003). However, we need to be equally attuned when biomedicine and biotechnology appear to be promoting our ‘reproductive freedom’ through commercialized advances, including Assisted Reproductive Technologies (ART). Thus far, cases in the Inter-American Court of Human Rights and the European Court of Human Rights² have generally been framed in terms of enabling women who may be infertile or past reproductive age, non-heteronormative couples, or people facing a serious genetic disease to have ‘families’—as part of their rights to dignity, privacy and self-determination, with clear synergies between some of these cases and abortion rights (Oja and Yamin 2016). Such cases will inexorably proliferate with the ever-accelerating pace of all kinds of assisted reproductive technologies, from uterus transplants to ‘mitochondrial replacement therapy’ (which uses part of the ovum from the ‘mother’ and part from an egg donor, together with sperm—so-called ‘three-parent IVF’) to In Vitro Gametogenesis (which allows embryos to be ‘manufactured’ en masse from, for example, skin cells without the need for sexual intercourse) (Kang et al. 2016; New York Times Editorial Board 2019; Greeley 2018).

It would be counterproductive to suggest that feminists or human rights activists of varying races, gender identities and sexual orientations, could—or should—adopt a unified position with respect to the promises and perils of all of these distinct technologies. Nonetheless, in broader deliberations, we should be attentive to how the biomedical narrative of health, by treating health as an individualized biological issue, lends itself to the

1 The Argentina law, Integral Law for the Sanction, Prevention, and Eradication of Violence against Women (2009), defines reproductive processes as pregnancy, labour, childbirth, and post-partum periods.

2 For an example from the Latin American context, see *Artavia Murillo y Otros v. Costa Rica* (2012); for an example from the European context, see *Costa and Pavan v. Italy* (2012).

ever-greater commercialization of all forms of health care (Chapman 2016). Moreover, just as in ‘obstetric violence’, in ART the biomedical model treats clinicians as the subjects, and in turn parts of humans as products, and women’s bodies into fields of intervention. Further, even when we are talking about diverse families (such as same-sex couples), are we reifying the notion of genetically related parent–child relationships as the basis of the nuclear family? For example, the European Court of Human Rights has notably reinforced the importance of genetic links in its jurisprudence (Hart 2009). In short, the biomedical model systematically de-links human sexuality and identity from the social structures and the asymmetries in power (fostered by the economic organization of our national and global economies) under which women (and men) make decisions about reproduction (ibid.).

These are not academic matters, and they go far beyond reproductive rights advocacy. For example, when biomedicine promises a future of ‘disease-free’ children—in line with species-normal functioning—that inexorably creates a narrative of ‘less than fully-equal’ about existing and future persons with disability. Genetic modifications and other forms of artificial intelligence technology actually may in the not-too-distant future lead to forms of *othering* that are scientifically, as opposed to culturally or socially, generated. Will the advances made by activists and advocates before, and particularly since, the groundbreaking Convention on the Rights of Persons with Disabilities—to shift from treating disability as an individual impairment or defect to a product of an individual’s interaction with his or her environment, both material and symbolic (Shakespeare 2010; Estreich 2019)—be lost? Will the needs of persons with diverse (dis)abilities be (in)visibilized and legislative and policy measures (which inevitably cost money) be questioned in different contexts?

4. The social construction of population health within and between countries

4.1 Conventional public health and social change

Epidemiology, the science of public health, studies the determinants and distributions of disease within and across populations. Just as human rights have an ambivalent relationship with biomedicine, so too are epidemiological tools critical to human rights in showing disparities that may be tied to discrimination. Yet as Jonathan Mann, one of the founders of the ‘health and human rights’ field, noted over 20 years ago, conventional public health often takes the social order as a given, and thus, to paraphrase Mann, the question gets posed as ‘we have a maternal mortality (or x, y, z) problem, what are we going to do about it?’ (Mann et al. 1994). Thus, inexorably, conventional public health measures tend to be instrumental—that is, how do we improve outcomes?—and too often do not challenge the fundamental causes of patterns of health and ill-health, such as the underlying racialized class inequities that drive disparities, or the underlying economic organization within and across society that drives control of resources and capacities of states to respond.

Just as biomedicine focuses on the biological and, increasingly, the genetic level, mainstream public health largely focuses on proximate determinants, such as healthy behaviours, attitudes and information. For example, a 2019 editorial in the British Medical Journal (*BMJ*) questioned the overprescription of medical treatments and argued for an array of behavioural changes (Godlee 2019). To be clear: human rights advocates who work in this health space support demedicalizing treatment of diseases such as hypertension, and

regulating and taxing alcohol, tobacco and sugary beverage industries far more robustly insofar as those revenues are equitably reinvested back into public health (Marten et al. 2018). Indeed, the Framework Convention on Tobacco Control (WHO 2005) can also be considered a triumph for the primacy of health and health rights. Nonetheless, when we define public health in terms of ‘collective responsibility for the set of options from which individuals choose healthy and unhealthy behaviors’ (Gostin et al. 1999: 120)—even if there are mentions of the social and economic organization of societies—the emphasis on choosing unhealthy *behaviours* depoliticizes our understanding of how social and political determinants of health function (WHO 2008; Ottersen et al. 2014). As Nancy Krieger, a leading eco-social epidemiologist, writes: ‘[d]riving health inequalities are how power—both power over and power to do, including constraints on and possibilities for exercising each type—structures people’s engagements with the world and their exposures to material and psychosocial health hazards’ (Krieger 2008: 223). These engagements with the world go far beyond behaviours and built environments to social norms and institutional arrangements, for example.

4.2 What are the implications for human rights practice?

Let’s take an example of what might seem at first glance like an entirely behaviour-related health issue from the United States, a wealthy country. For the first time in decades, scholars have recently noted an increase in all-cause mortality of whites with a high school education or less in the United States. Anne Case and Angus Deaton dubbed these ‘deaths of despair’ as they are due to an epidemic of not just opioid overdoses, but also alcohol-related and suicide deaths (Case and Deaton 2017: 398). Conventional public health approaches would include some combination of: expanding treatment as well as prevention services; increasing public information; promoting provider/patient attitude and behaviour changes; and regulation of the marketing of alcohol, painkillers, and firearms where possible. Of course, these measures are important. Further, in accordance with human rights concerns of non-discrimination, oversight and regulation must be done in ways that avoid harming those—generally in lower income and marginalized groups—who need chronic pain medications (Oliva 2019 (forthcoming)). Yet, if human rights stop there, we are adding window dressing to conventional approaches that do not challenge the status quo.

By contrast, if we take seriously the social construction of health, we would look to the work of economists, sociologists, historians and others to understand the dynamics of political and economic power that led us to be where we are. For example, Case and Deaton argue that ‘deaths of despair come from a long-standing process of cumulative disadvantage’, including decreased unionization and wage power, community supports, and most centrally a college education (Case and Deaton 2017: 2). In other words, the bottom line is that decades of upward redistribution of wealth—fostered by neoliberal economic policies that have reduced fiscal space and led to disinvestment in basic education and social protection, encouraged relocation of industry based on trade agreements, and furthered deregulation—are now showing extraordinary health effects. The epidemic of deaths of despair in the United States fundamentally needs to be treated not just with expanding treatments, opportunities for behaviour change and awareness-raising, or merely punitive accountability for pharmaceutical companies. It requires fiscal and social interventions beyond the health system that create opportunities for education and employment, now and in the future—and redistribute income across society, and social mobilization for civic

re-engagement. One recent study suggested that increasing the minimum wage and the Earned Income Tax Credit by ten per cent would likely prevent around 1,230 non-overdose suicides each year (Dow et al. 2019).

These findings are not surprising given that in 2017 Wall Street's investment banking firms handed out 23.9 billion US dollars in bonuses to their employees, while the *Washington Post* noted the average bonus was triple what most US households made for the entire year (Merie 2018). That egregious inequity drives alienation, anger and despair among those who can no longer hope to have stable decent work with pensions after retirement, good public schools for their kids, or community supports—which underpins addiction and suicides. But of note, that same anger also fuels identity politics, populist distrust of institutions and backlash against ideologically charged or transgressive issues, such as sexual and reproductive health rights. In a wealthy country such as the United States, these are political choices. Choices can be changed by connecting the idea of human rights in health with different kinds of allies, including labour movements, and by more politics-centred advocacy that rejects neoliberalism's articles of faith.

In contrast, reducing human rights in health to 'added value' in efforts to improve health outcomes (by including concern for marginalized populations or considerations of equity through disaggregation) is not only a strategic mistake because health-related rights are then silo-ized in 'health', perceived as irrelevant to broader struggles for meaningful democracy and social justice. It is also an epistemic mistake because the end goal in rights advocacy is enabling ordinary and diverse people to live with *dignity*—which includes but goes beyond the conditions for *healthy* lives.

4.3 What are the implications for human rights advocacy regarding health systems more broadly in an era of austerity?

Not all countries have the same political flexibility to change fiscal and monetary, as well as social, policies. Today, 80 per cent of the global population is living under some form of austerity or 'fiscal consolidation'—which is part of the prescriptions of international financial institutions (UN Human Rights Council 2017: para. 19). As the Center for Economic and Social Rights has noted, austerity affects population health in multiple ways, including: (1) in the health system through wage cuts and layoffs of health personnel; increase in co-pays and out-of-pocket expenses; reducing benefit packages; changing eligibility criteria; disrupting access to insurance; and cuts to mental health, reproductive health or other services that affect excluded communities; (2) through cuts to environmental protection and water and sanitation infrastructure, as well as safety, which affect public health; (3) indirectly through cuts in the education sector, reduction of food assistance and security programmes and through reducing funding of temporary housing/shelters and housing subsidies; and (4) generally through reduced unemployment support and tightening of 'targeted' social programmes (CESCR 2018). And as we know, economic inequalities are reinforced by urban–rural, education, race, and gender inequalities. All of these effects are social determinants of health—'the conditions in which people are born, grow, live, work and age' (WHO 2008)—including the effects on health systems.

In conventional public health, health systems are generally conceptualized as apparatuses for the delivery of technical interventions to improve population health outcomes. But health systems, like justice systems and all other social institutions, do much more than that (Freedman 2005). Health systems can exacerbate exclusion and inequality—or alternatively

weave together social (that is, long-term migrants irrespective of their legal status) and legal citizens in society. They inevitably reflect and refract the normative values in society, and understanding how to shape those institutions is fundamental to health rights advocacy.

As noted by the People's Health Movement (PHM), Universal Health Coverage (UHC) is 'in many countries, being implemented by private health insurance companies and aggravating health inequities' (Alternative Civil Society 2018: 1). Indeed, as austerity has increasingly restricted government budgets, privatization of financing, insurance coverage and care has come to play a huge role in the implementation of UHC initiatives around the world, which will foreseeably exacerbate inequalities unless there is effective and robust regulation in practice. Since the year 2000, when the UN asked the private sector to 'partner with the UN' through the Global Compact, the importance of the private sector, and the neoliberal narrative that the private sector is better than the public sector at many of the structural charges related to health, has been progressively embedded and taken for granted in global health. As a result, UHC is being delivered through private insurance and private providers (or public-private partnerships) in countries from India to Uganda, without effective and robust regulation. As a recent report from the non-governmental Initiative for Social and Economic Rights in Uganda finds, the private insurers and providers have incentives for profit, which rarely overlaps with systemic equity (ISER 2019: 6).

My point here is that the epistemic understanding of health systems has political consequences. That is, if we accept the neoliberal principle that health systems can be governed by commercial or technical imperatives, human rights in practice will always be consigned primarily to exposing cases that 'shock the conscience'. We have seen any number of such cases, from post-partum women being detained for non-payment of fees,³ to privatized care for persons with mental disabilities being degrading to the point of people dying,⁴ or exploitative marketing of opioids in the United States.⁵ Of course such instances are critical to denounce as 'manifest injustice' (Sen 2009).

However, from a more transformative human rights perspective, privatization of care and private finance must be understood within the context of the underlying purpose of the system. That is, if health is a right—inextricably related to a life of dignity—it is not just that adjustments at the margins need to be made to mitigate the most egregious market failures (Chapman 2016). It is that fairness cannot be determined by the market and ability to pay. Full stop. In short, not only is the increasingly common refrain that UHC is the materialization of the right to health simply not true;⁶ we need to be attuned to the effects of ways in which UHC is being financed and implemented, and then devise concerted politics-centred strategies at national and international levels with allies in social movements—both labour movements and across subject areas (many of the same issues apply to education)

3 This case, *M. A. O. & Another v. Attorney General & Four Others* (Kenya), was decided in 2015.

4 *Families of Mental Health Care Users Affected by the Gauteng Mental Marathon Project v. National Minister of Health of the Republic of South Africa and Three Others* (2018) was decided by arbitration before Justice Dikgang Moseneke, who awarded each claimant over one million South African rand in compensation.

5 For one example, see *State of Oklahoma v. Purdue Pharma LP*, No. ZCJ-2017-816, Oklahoma District Court for Cleveland County (Norman), which settled in March 2019 for 270 million US dollars.

6 As Dr Tedros Adhanom Ghebreyesus, Director-General of the WHO, has said, such as in his 2017 inaugural address (WHO 2017).

(Moon et al. 2017). To be clear: this does not mean there is no role for the private sector, but the private sector is most accountable when there is vigorous oversight and regulation by the state.

4.4 What are the implications for human rights advocacy regarding global health equity?

Just as health is a sensitive reflection of social (in)equity in any given community, the gaping disparities in global health keenly reflect a global political economy that has been disfigured by decades of policies that, among other things, have deregulated economies and trade, flexibilized labour, and hollowed out fiscal space and the capacity for meaningful oversight and democratic governance. Let's take perhaps the most extreme example of health inequity: Ebola in the Democratic Republic of Congo (DRC). The outbreak that began in 2018 started to grow out of control, accelerating as fighting between government forces and guerrillas in the eastern DRC surged in the spring of 2019, including attacks on health centres (Inglesby and Nuzzo 2019).

First, the Ebola outbreak is clearly driven by poverty, conflict, cultural beliefs and other social and political determinants of health. This outbreak, as others have been, is gendered in its effects as women are more likely to be first-line health workers and caregivers at home who come into contact with Ebola; they are also more likely to come into contact with the health system for other needs, reproductive and child health-related, and therefore to be affected indirectly. Changing behaviours (such as burial practices, or attitudes) is an inherently limited approach, especially when the health system is viewed with the same suspicion as the government in a country ravaged by war for close to two decades (Grady 2019). The health system, once again, is clearly not just an apparatus for the delivery of interventions—such as what has proven to be a highly effective experimental vaccine (Branswell 2018). Moreover, it is too late in an acute emergency to expect people to trust what is said by the same authorities who have lied to them before. It is not surprising that many of the dead have been found never to have sought care (Grady 2019).

Nonetheless, the International Health Regulations (IHR) (WHO 2007), which bind members of the WHO, are intended in part to require the international community to take measures not in the acute phase of emergencies but in between epidemics. Article 44 of the IHR, in particular, sets out a duty of 'assistance and collaboration' in building countries' core capacities to deal with such epidemics. Many in human rights have tended to focus on international obligations to supplement domestic resources available in poor countries, here and elsewhere. Gorik Ooms and Rachel Hammonds have argued that the Global Fund to Fight AIDS, Tuberculosis and Malaria—the same Global Fund Peter Sands is now eagerly looking to bolster with corporate investment—provides a model of such 'sustainable financing' to meet countries' core obligations (Ooms and Hammonds 2018). But what is really driving the conflict in eastern Congo—and in turn Ebola—are the mineral deposits, including coltan, which is used in computers and cell phones, and as mobile phone use has expanded the conflict in the region has deepened (Garrett 2019). Of course we need to address immediate suffering more effectively; of course donor countries should provide greater assistance and cooperation for core health capacities—and more. But the point is that palliative financial assistance lets too many actors off the hook. Among numerous other things, governments in the economic North need to take more effective measures (in addition to those resolutions and regulations they have passed) to stop the importation and

use of such conflict minerals in cell phones and computers and address the natural resource exploitation, as well as other underlying factors in the underdevelopment and lack of democratic institutions in the DRC.

The same logic applies more broadly to the political economy of global health. For example, tax evasion, in particular by transnational corporations, removes more money from sub-Saharan Africa than could be garnered in aid. Indeed, blended finance investments for UHC and other parts of the SDGs often are contingent upon tax breaks, and donors routinely seek tax exemptions from the same countries to which they are providing aid or grants, which could amount to two or three per cent of some countries' tax revenue. These kinds of exemptions would likely not even be counted as 'illicit' financial flows, which Global Financial Integrity asserts amounted to 1.1 trillion US dollars in 2013, dwarfing total development assistance for health (GFI, no date). Yet countries in the economic North routinely block efforts to systematically address multinational tax evasion and illicit financial flows under the SDGs, blaming the countries in the global South.

In short, taking seriously the political economy of global health points to the need for health rights advocacy to combine forces with groups focusing on the rules of global economic governance, such as trade and tax, as opposed to narrow solutions to meet so-called 'core health needs', which reinforce sufficientarianism (Meyer 2009: 133), and do not challenge the neoliberal political economy of global health.⁷

5. Concluding reflections

Many recent critiques of human rights by progressives, Marxists and others, understate the critical importance of diverse, ordinary people, often from subaltern groups, appropriating a sense of their own agency and capacity to collectively change the world (Dugard 2019). Moreover, in decades of fieldwork, people who describe the experience of living without rights do so not merely in terms of access to goods or services, but in terms of shame, degradation, indignity, and, perhaps most of all, powerlessness over their lives and those of their loved ones. Yet meaningful power has never been given away, and it is an illusion to seek to use health rights in bureaucratic and modular fashion, disconnected from political contestation over fundamental distributive issues. Movements for labour rights, civil rights, women's rights, and the like have always entailed struggles to deepen and broaden democracy. And health has historically often been explicitly an integral part of such struggles. Women's movements fought for access to contraception and abortion; labour movements fought for health coverage; and health systems have been seen as integral to post-conflict or post-dictatorship aspirations, from European welfare states to the social medicine championed in Latin America.

Direct action and civil disobedience—where live human beings occupy public space and literally embody demands—has always been and will remain central to health (and other)

7 Moreover, the Global Fund to Fight AIDS, Tuberculosis and Malaria, on which such arguments for a more encompassing facility are based, is deeply problematic in how it is funded and to whom it is accountable, even if it does have a civil society/NGO Forum. For example, when the current director, Peter Sands, who has actively sought out greater private finance for the Global Fund, suggested in a March 2019 *Fortune* magazine op-ed (Jha and Sands 2019) that the entire global health community needs to engage the private sector more successfully, it was indicative of how far this shift in global health governance has gone.

rights struggles, from the massive HIV protests in years past to the mass protests in favour of abortion and sexual and reproductive health rights in Argentina and across Latin America over the last few years (Politi and Londoño 2018). Our capacity for outrage and collective protest is vital to democracy—and to our humanness. However, the progress we have made in the intersections of health and rights has also been due to re-examining assumptions in both human rights law and medical and public health paradigms, and to shaking up habitual ways of working and thinking. From the struggles of people living with HIV to many issues in sexual and reproductive health rights, what was once impossible is now taken for granted.

Today, we face not only counter-mobilization, but resurgent forms of oppression and discrimination, climate cataclysm, as well as loss of belief in democratic and multilateral institutions. However, the threat we collectively face, which interacts with all the others, is the neoliberal architecture of our national and world orders. The neoliberal version of capitalism leaves ever-deepening inequalities in its wake, treats the planet and much of what is in it as commodities to be commercialized, and makes large swathes of human beings and their rights irrelevant to ‘economic progress’. I have argued that orthodoxies in biomedicine and conventional public health interact with these neoliberal policies at national and global levels, so that we need to collectively strategize about how to use human rights in ways that challenge and do not merely sanitize that reality. As Amy Kapczynski writes, ‘a more transformative human rights movement must go beyond simple attention to socioeconomic rights. It requires attention to the structural changes that are needed to reform our political economy, and to provide the infrastructure for fair provision, locally and globally, that neoliberal legality has steadfastly opposed’ (Kapczynski 2019). In this time of extraordinarily rapid change and geopolitical dislocation, we in the diverse communities that work at the intersections of the multiple fields around health and human rights have the opportunity for critical reflection on our achievements to date and for epistemic disruption of entrenched beliefs, including how possibilities for dignity are shaped and internalized by framings of the world in medicine and public health.

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References

- Alston, P. 2017. The Populist Challenge to Human Rights. *Journal of Human Rights Practice* 9(1): 1–15.
- Alternative Civil Society. 2018. Astana Statement on Primary Health Care.
- Artavia Murillo y Otros v. Costa Rica (Inter-American Court of Human Rights, Judgment of 28 November 2012, Series C No. 257).

- Baker, A. 2017. A Liberian Ebola Fighter, a TIME Person of the Year, Dies in Childbirth. *Time*. 27 February.
- Borowy, I. 2014. Shifting between Biomedical and Social Medicine: International Health Organizations in the 20th Century. *History Compass* 12(6): 517–30.
- Branswell, H. 2018. Experimental Vaccine to be Used against Ebola Outbreak in the DRC. STAT News. 13 May.
- Case, A., and A. Deaton. 2017. Mortality and Morbidity in the 21st Century. *Brookings Papers on Economic Activity*.
- CESCR (Center for Economic and Social Rights). 2018. Assessing Austerity: Monitoring the Human Rights Impacts of Fiscal Consolidation.
- Center for Reproductive Rights. 2018. Kenya's High Court Rules in Favor of Woman Physically Abused During Delivery. <https://www.reproductiverights.org/press-room/kenya-high-court-rules-in-favor-of-woman-physically-abused-during-delivery> (referenced 6 May 2019).
- Chapman, A. 2016. *Global Health, Human Rights, and the Challenge of Neoliberal Policies*. Cambridge University Press.
- Convention on the Rights of Persons with Disabilities, adopted 13 December 2006 (entered into force 3 May 2008).
- Costa and Pavan v. Italy* (European Court of Human Rights, Application 54270/10, Judgment of 28 August 2012).
- Dasgupta, J., Y. K. Sandhya, S. Lobis, P. Verma, and M. Schaaf. 2015. Using Technology to Claim Rights to Free Maternal Health Care: Lessons about Impact from the My Health, My Voice Pilot Project in India. *Health and Human Rights Journal* 17(2) (online).
- Dow, W., A. Godoy, C. Lowenstein, and M. Reich. 2019. Can Economic Policies Reduce Deaths of Despair? NBER (National Bureau of Economic Research) Working Paper No. 25787.
- Dugard, J. 2019. Human Rights—Tackling Inequality by Catalyzing the Agents of Social Change. Open Global Rights. 12 February. <https://www.openglobalrights.org/human-rights-tackling-in-equality-by-catalyzing-the-agents-of-social-change> (referenced 3 July 2019).
- Estreich, G. 2019. *Fables and Futures: Biotechnology, Disability, and the Stories We Tell Ourselves*. Cambridge, MA: MIT Press.
- Families of Mental Health Care Users Affected by the Gauteng Mental Marathon Project v. National Minister of Health of the Republic of South Africa and Three Others* (2018). Arbitration award. (South Africa). <http://www.saflii.org/images/LifeEsidimeniArbitrationAward.pdf> (referenced 3 July 2019).
- Farmer, P. 2004. *Pathologies of Power: Health, Human Rights, and the New War on the Poor*. University of California Press.
- Forbath, W. 2010. Cultural Transformation, Deep Institutional Reform, and ESR Practice: South Africa's Treatment Action Campaign. In L. White and J. Perelman (eds), *Stones of Hope: How African Activists Reclaim Human Rights to Challenge Global Poverty*, pp. 51–90. Stanford University Press.
- Forman, L. 2008. 'Rights' and Wrongs: What Utility for the Right to Health in Reframing Trade Rules on Medicines? *Health and Human Rights Journal* 10(2): 37–52.
- Foucault, M. 1973. *The Birth of the Clinic: An Archaeology of Medical Perception*. Paris: Presses Universitaires de France.
- Freedman, L. P. 2005. Achieving the MDGs: Health Systems as Core Social Institutions. *Development* 48(1): 19–24.
- Garrett, L. 2019. Your Cellphone is Spreading Ebola. *Foreign Policy*. 17 April.
- GFI (Global Financial Integrity). No date. Analytical Methodologies Utilized by Global Financial Integrity. <https://www.gfintegrity.org/issues/illlicit-financial-flows-analytical-methodologies-utilized-global-financial-integrity> (referenced 6 May 2019).
- Godlee, F. 2019. Pills or Public Health? *BMJ* (British Medical Journal) 365: 1791.

- Gostin, L., S. Burris, and Z. Lazzarini. 1999. The Law and the Public's Health: A Study of Infectious Disease Law in the United States. *Columbia Law Review* 99(1): 59–128.
- Grady, D. 2019. The Battle Against One of the Worst Ebola Epidemics Ever is in Trouble. *New York Times*. 7 March.
- Greeley, H. 2018. *The End of Sex and the Future of Human Reproduction*. Cambridge, MA: Harvard University Press.
- Hardoon, D., R. Fuentes-Nieva, and S. Ayela. 2016. An Economy for the 1%: How Privilege and Power in the Economy Drive Extreme Inequality and How This Can Be Stopped. Oxfam.
- Hart, L. 2009. Individual Adoption by Non-Heterosexuals and the Order of Family Life in the European Court of Human Rights. *Journal of Law and Society* 36(4): 536–57.
- Inglesby, T., and J. Nuzzo. 2019. Urgent Steps are Needed to Prevent Ebola from Spinning Out of Control in the DRC. STAT News. 3 May.
- ISER (Initiative for Social and Economic Rights). 2019. Achieving Equity in Health: Are Public Private Partnerships the Solution? Kampala, Uganda.
- Jha, A., and P. Sands. 2019. Most CEOs Don't Have a Global Health Strategy. That Needs to Change. *Fortune*. 25 March. <http://fortune.com/2019/03/25/private-sector-global-health-strategy> (referenced 6 June 2019).
- Kang, E., J. Wu, N. Marti Gutierrez, A. Koski et al. 2016. Mitochondrial Replacement in Human Oocytes Carrying Pathogenic Mitochondrial DNA Mutations. *Nature* 540: 270–5.
- Kapczynski, A. 2019. Access to Medicines in a Neoliberal Age. *Humanity* 10(1): 79–107.
- Klein, N. 2007. *The Shock Doctrine: The Rise of Disaster Capitalism*. New York: Picador.
- Krieger, N. 2008. Proximal, Distal, and the Politics of Causation: What's Level Got to Do with It? *American Journal of Public Health* 98(2): 221–30.
- Magar, V., S. Heidari, G. Zamora, A. Coates et al. 2019. Gender Mainstreaming within WHO: Not without Equity and Human Rights. *The Lancet* 393(10182): 1678–9.
- Malacrida, C., and T. Boulton. 2014. The Best Laid Plans? Women's Choices, Expectations and Experiences in Childbirth. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness, and Medicine* 18(1): 41–59.
- Mann, J., D. Tarantola, and J. O'Malley. 1994. Towards a New Health Strategy to Control the HIV/AIDS Pandemic. *Journal of Law, Medicine & Ethics* 22(1): 41–52.
- M. A. O. & Another v. Attorney General & Four Others (High Court of Kenya at Nairobi, Constitutional and Human Rights Division, Petition No. 562 of 2012, 17 September 2015).
- Marten, R. et al. 2018. Sugar, Tobacco, and Alcohol Taxes to Achieve the SDGs. *The Lancet* 391(10138): 2400–1.
- Martin, K. A. 2003. Giving Birth Like a Girl. *Gender and Society* 17(1): 54–72.
- Meier, B. M., and L. Gostin. 2018. Framing Human Rights in Global Governance. In *Human Rights in Global Health: Rights-Based Governance for a Globalizing World*, pp. 63–86. Oxford University Press.
- Meier, B. M., and W. Onzivu. 2014. The Evolution of Human Rights in World Health Organization Policy and the Future of Human Rights through Global Health Governance. *Public Health* 128(2): 179–87.
- Merie, R. 2018. Wall Street's Average Bonus in 2017? Three Times What Most US Households Made All Year. *Washington Post*. 26 March.
- Meyer, L. 2009. Sufficiencyarianism Both International and Intergenerational? In E. Mack et al. (eds), *Absolute Poverty and Global Justice: Empirical Data, Moral Theories, Initiatives*, pp. 133–45. Routledge.
- Minister of Health v. Treatment Action Campaign* (Constitutional Court of South Africa, case CCT 9/02, 5 July 2002).
- Moon, S., D. Kirpalani, and E. Erickson. 2017. Business and Health through Economic and Political Lenses: Concepts, Problems, and Strategies for Governance. Geneva: Graduate Institute of International and Development Studies.

- Moyn, S. 2018. *Not Enough: Human Rights in an Unequal World*. Cambridge, MA: Harvard University Press.
- New York Times Editorial Board. 2019. This Editorial is Not About Designer Babies. *New York Times*. 12 April 2019.
- Odallo, B., E. Opondo, and M. Onyango. 2018. Litigating to Ensure Access to Quality Maternal Health Care for Women and Girls in Kenya. *Reproductive Health Matters* 26(53): 123–9.
- Oja, L., and A. E. Yamin. 2016. ‘Woman’ in the European Human Rights System: How is the Reproductive Rights Jurisprudence of the European Court of Human Rights Constructing Narratives of Women’s Citizenship? *Columbia Journal of Gender and Law* 32(1): 62–95.
- Oliva, J. 2019 (forthcoming). Prescription Drug Policing: The Right to Health Information Privacy Pre- and Post-*Carpenter*. *Duke Law Journal* 69.
- Ooms, G., and R. Hammonds. 2018. The Future of Multilateral Funding to Realize the Right to Health. In B. Meier and L. Gostin (eds), *Human Rights-Based Governance in a Globalized World*, pp. 441–60. Oxford University Press.
- Ottersen, O. P., J. Dasgupta, C. Blouin, P. Buss et al. 2014. The Political Origins of Health Inequity: Prospects for Change. *The Lancet* 383(9917): 630–67.
- Polet, F., G. Malaise, A. Mahieu, E. Utrera et al. 2015. Empowerment for the Right to Health: The Use of the ‘Most Significant Change’ Methodology in Monitoring. *Health and Human Rights Journal* 17(2): 71–82.
- Politi, D., and E. Londoño. 2018. They Lost Argentina’s Abortion Vote, but Advocates Started a Movement. *New York Times*. 9 August.
- Samuel, J., and A. Frisancho. 2015. Rights-Based Citizen Monitoring in Peru: Evidence of Impact from the Field. *Health and Human Rights Journal* 17(2): 123–34.
- Sen, A. 2009. *The Idea of Justice*. Cambridge, MA: Harvard University Press.
- Shakespeare, T. 2010. The Social Model of Disability. In L. Davis (ed.), *The Disability Studies Reader*, pp. 197–204. Routledge.
- State of Oklahoma v. Purdue Pharma LP*, 2017, No. ZCJ-2017-816, Oklahoma District Court for Cleveland County (Norman).
- UN Development Group. 2003. The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies.
- UN Human Rights Council. 2012. Technical Guidance on the Application of a Human Rights-Based Approach to the Implementation of Policies and Programmes to Reduce Preventable Maternal Morbidity and Mortality. A/HRC/21/22.
- . 2017. Report of the Independent Expert on the effects of foreign debt and other related international financial obligations of states on the full enjoyment of all human rights, particularly economic, social and cultural rights. A/HRC/37/54.
- Universal Declaration of Human Rights, adopted by UN General Assembly resolution 217A(III), 10 December 1948.
- Vacaflor, C. H. 2016. Obstetric Violence: A New Framework for Identifying Challenges to Maternal Healthcare in Argentina. *Reproductive Health Matters* 24(47): 65–73.
- WHO (World Health Organization). 1946. Constitution.
- . 2005. Framework Convention on Tobacco Control.
- . 2007. International Health Regulations.
- . 2008. Closing the Gap in a Generation: Commission on Social Determinants of Health Final Report.
- . 2017. Director-General Dr Tedros Takes the Helm of WHO: Address to WHO Staff.
- Yamin, A. E. 1997. Transformative Combinations: Women’s Health and Human Rights. *Journal of the American Medical Women’s Association* 52: 169–73.
- Yamin, A. E., and R. Cantor. 2014. Between Insurrectional Discourse and Operational Guidance: Challenges and Dilemmas in Implementing Human Rights-Based Approaches to Health. *Journal of Human Rights Practice* 6(3): 451–85.