Health and Human Rights' Past: Patinating Law's Contribution

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Abstract

This article argues that to be able to look forward, lawyers within the health and human rights movement need to do more looking back. It is prompted by a simple question: do we have a history of health and human rights law and lawyering? Finding nothing that qualifies, the article asks how we might fill that gap. Focusing on international human rights law, it prescribes histories of health and human rights law "favorites," notably the international human right to health and human rights-based approaches to health. It also prescribes histories of neglect: histories exploring the low levels of attention to certain issues, such as the right to science, that seem directly relevant to health and human rights. The article emphasizes that neither of these history projects should be a search for origins or an opportunity to pitch linear "onwards and upwards" accounts of health and human rights law. The prescription is for histories that are open to the ebb and flow of particular international human rights law norms and approaches as they have come into being and crisscrossed the United Nations and beyond.

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Introduction

Some say that this is the age of human rights; others insist that the age of rights is over, disappearing, or stalled at least for now. Taking a critical but enabling stance on the matter is hard, and in international human rights law circles in particular, the mood is downbeat. Little has been going well, and the field feels assailed on all fronts. Its credentials have been hit hard amid a pullback from internationalism and international institutions.[1] Conceived as "palaces of hope," international institutions are now less likely to be held up as rational and efficient, and more likely to be seen as remote from those who need protection, weak when faced with power, unduly focused on funding, and mired in round after round of reform.[2] At the same time, populist-authoritarian governments are on the rise; so, too, are understandings of sovereignty that foreground non-interference and state-led development. Further, all parts of the world have seen moves against both human rights and environmental defenders.[3] Internationally, governments of various political colors continue to make attempts to deplete human rights standards. Human rights proponents, too, have issued calls for restraint, raising concerns that the proliferation of new rights and, more broadly, the tendency to frame so many problems in human rights terms create an overload that damages the credibility of rights.[4]

There is also a volubility to longstanding criticisms of international human rights law. These criticisms ridicule norms that are said to be imprecise and ambiguous and subject to allegedly laughable standards such as "progressive realization." They also point to a chronically unconvincing enforcement architecture and to routine violations, which are cited as evidence of the general ineffectiveness and lack of impact of this legal field.[5] Recently, a spate of critical histories of human rights has deepened international human rights law's problems.[6] Relatedly, across the world, tough questions have been raised by the persistence of "geographies of injustice" and by the growing gap everywhere between the rich and the rest.[7] One question in particular has been hitting home: has the human rights movement settled for sufficiency (that is, for "just enough" or a "minimum core"), sloping away from questions of political economy—above all, how to address economic inequality, including the ways in which it intersects with other inequality drivers such as gender, disability, and sexual orientation?[8]

This is my departure point. In this article, I ask, is health and human rights law and lawyering adequate to this present and prepared for the future? Focusing on international human rights law, I suggest that we are competent in many ways, but there is one way in which we are not: we have no history of health and human rights law and lawyering. And so, insisting that we "read the future by the past," I ask how this gap might be filled.[9] There are a number of options. For instance, we should read, learn from, and respond to more work by historians on aspects of the broader health and human rights movement: historians including Sunil Amrith, Alison Bashford, and Eileen Boris and Jennifer Klein.[10] And we should learn about historical methodology, from what it means to write genealogically, to the pros and cons of microhistories.[11] Here, however, I focus on a third option: areas we could foreground in our history writing. I nominate two. The first is histories of health and human rights law "favorites," such as the right to health and, more broadly, human rights-based approaches to health. And the second is histories of neglect or omission, in particular the right to science, and relatedly how international human rights law relates to technology and how ethics, as a regulatory tool widely advocated in the field of science and technology, relates to international human rights law.

I say something about mindset too. The histories prescribed here have to be genealogical. This means they will not obsess about origins, breakthroughs, or linear development, and they will not lapse into "happy ever after" or "doom and gloom." Instead, they will attend simultaneously to continuity and change over time. Equally, they will not leap from one aspect of international human rights law to the next, from one instrument, judgment, or treaty body communication to the next. That would make us incurious about how particular laws have been generated, bolstered, stripped back,

or, more broadly, co-produced by social practices and popular understandings.[12] If we are to cultivate legal literacy, a different approach will be needed, one that is open to experience—to the emergence, deflection, distortion, and even destruction of particular human rights law norms and approaches as they have traveled across the United Nations (UN) and beyond and have been transformed in the process and perhaps been transformative too.

Doing things differently?

I want to begin by challenging the mood of the moment as regards international human rights law. For lawyers like me whose work relates to health and human rights, international human rights law feels far from a dead end. We show no signs of disengagement either from law in general or from international human rights law in particular. Moreover, economic, social, and cultural rights, still widely neglected in many other human rights law circles, continue to be center stage for us. There is, for example, palpable interest in generative concepts associated with the right to health—from availability, accessibility, acceptability, and quality (collectively known as AAAQ), to maximum available resources, progressive realization, and international assistance and cooperation. Interest continues to cascade toward other human rights too, which is welcome because it eases the pressure created by the embrace of the underlying determinants of health within the right to health.[13] It also builds appreciation of the independent role of other human rights in achieving the aims of the health and human rights movement. A further welcome feature is the span of health and human rights lawyers' engagement: stretching across "crisis" and "the everyday," it encompasses not just pandemic prevention and preparedness but also the quotidian violations produced, for example, by user fees in health care or lack of respect for dignity in childbirth.

Health and human rights lawyers' multi-institutional approach stands out too. True, there were lean years when commentary on access-to-medicines litigation felt too dominant (albeit the backdrop was one of extreme doubt as to whether judges would hear cases concerning economic, social, and cultural rights). Yet, even then, there was little sense of health rights litigation as a single phenomenon, in part because commentators generally ranged beyond exemplars (namely, courts in South Africa and India), and in part too because commentators looked at both international and national courts, including how they were interacting. Relatedly, commentators examined more than the judiciary, extending their range to include both civil society's engagement with law and the ways in which domestic judicial attitudes were affected by the nature and quality of local political leadership.

Overall, however, in the lean years, there was a sense of commentators having to be either "for" or "against" the judicialization of health. Fortunately, engagement with right-to-health litigation is now moving beyond this narrow approach. Today's engagements tend to be *in concreto*.[14] By this I mean that they draw out procedural issues and particular styles of judicial reasoning, including how different courts use (or do not use) international human rights law to navigate the minefield of judicial competency and legitimacy that surrounds health litigation. Today's engagements also draw out the ways in which litigation can be about more than access to medicines and individual demands. And they look "beyond judgment"—that is, beyond the text of judicial decisions toward compliance and even structural changes. Further, these explorations are now more likely to draw on a seam of non-legal perspectives and field experiences, which helps expand knowledge about right-to-health litigation and offers new ways of capturing, conceiving of, and responding to its heterogeneous nature.

To be fair, even in the lean years, health and human rights lawyers did range beyond courtroom walls. All branches of government were of interest; so too were a wide range of international institutions, not just the World Health Organization (WHO) and the human rights treaty bodies at the United Nations.[15] In addition, a focus on practical implementation led to interest in clinics, hospitals, prisons, and the like, while a focus on everyday accountability brought ombuds, regulators, and others into the picture. As a consequence, health

and human rights lawyers have knowledge, and more broadly a sensibility, that is sometimes missing in other human rights law circles—a sensibility that spans rights mobilization, planning, budgeting, programming, and monitoring, evaluation, and accountability.

Relatedly, when health and human rights lawyers speak about the past, sequences of law—the act of leaping from one law to the next—generally do not squeeze out everything else. There is no sense of a search for a starting point when health and human rights law began, or for a breakthrough or rupture indicating when it came to matter more than it had in the past. Similarly, although UN instruments, treaty bodies, and the like are well represented when we speak about health and human rights law, there is no sense of them as the only makers of health and human rights law history. People, nongovernmental organizations, events, objects, and more are present too.[16] More importantly, health and human rights lawyers have largely avoided human rights isolationism. By this, I mean four things: first, health and human rights lawyers typically place international human rights law within human rights law more broadly, including domestic and regional human rights law. They do not cleave to a separate-spheres model: instead, they recognize that different human rights legal orders work together (albeit in messy, sometimes conflictual, and always reversible ways) in order to promote and secure respect for human rights. They also recognize that as human rights law travels, it tends to be transformed, taking on different roles, and potentially different meanings, in individual states and international organizations.[17] This means that Geneva—international human rights law's "home town"—isn't always at the center: its human rights institutions are important, but mainly as leverage for work with other international actors and as places to develop links, tactics, and social capital, which can be put into play at the local level.

Second, health and human rights lawyers locate international human rights law within a broader international legal frame—as, for instance, when the drive for access to antiretrovirals targeted not just international human rights organizations but trade ones too. Third, although international human rights law has been widely invoked by health and human rights lawyers, we do not define ourselves through that idiom. We practice a kind of critical faith in the possibilities of law in general and international human rights law in particular. So, for example, we are committed to describing and developing the "legal determinants of health."[18] At the same time, however, we are averse to anything that smacks of law out-of-context. Similarly, we see the power—positive and negative—of law and legal institutions, but generally speaking we also see that power takes many other shapes and forms. And, at our best, we see that law's power can both complement and rub against other forms of power (including, for example, within a health clinic, a setting where non-legal rules and conventions are also in play) and is riven by endless internal tensions.[19]

Health and human rights lawyers' practice-oriented approach—which is our fourth key characteristic—helps enable this. In international human rights law circles more generally, a practice orientation tends to be contrasted with orientations that are philosophical or political. Typically, it signals an interest in looking at what courts do with rights. For health and human rights lawyers, being practice oriented means something different: it means an ethical commitment to give voice to human suffering and to ameliorate it.[20] If international human rights law serves that purpose—and there is evidence to indicate it can do so—then health and human rights lawyers take advantage of this field of law. But if other idioms or circuits seem relevant, we do not turn our back. So, for example, we engage with synonyms for human rights, including universal health coverage as a "practical expression of the concern for … the right to health."[21] This is a gamble fraught with tension, which is manageable only when strategy, tactics, and methods are considered in situated and concrete ways.

Is something missing?

So, there is much to praise in the practice of health and human rights law. At the same time, I sense that something is missing. Why is there no history

of health and human rights law and lawyering? And isn't it curious that this history is missing when elsewhere, for at least a decade, many have been working out (and sometimes griping about) what histories of human rights, and international law more generally, might be or might become?

It is not that we never write about our history. The problem is that what we write is monochrome. By and large, we foreground just one story when we recount health and human rights law past. This story places the role of human rights law in responding to the HIV/AIDS pandemic at center stage. Key parts are given to the Universal Declaration of Human Rights, General Comment No. 14 from the UN Committee on Economic, Social and Cultural Rights, the increasing number of constitutions that include a guarantee of the right to health, and access-to-medicines judgments from courts in South Africa, India, Brazil, Colombia, and Venezuela. References to key people and organizations follow a similar pattern: UNAIDS, WHO, the Global Fund to Fight AIDS, Tuberculosis and Malaria, the World Trade Organization, Jonathan Mann, the Treatment Action Campaign, and the like are repeat players. Our periodization also tends to be either "before and after" HIV/AIDS or during stages of the pandemic.

I would not want to exclude any of this; my concern is that its dominance downplays other significant parts of health and human rights law's history. Here are examples of what is left out: first, sexual and reproductive health and rights sometimes have no more than a walk-on role and are located almost exclusively in the context of either the HIV/AIDS pandemic or maternal health.[22] Second, distinctive characteristics of the right to health tend to be submerged by attention to the broader question of human rights-based approaches to health.[23] Third, regional human rights systems, including how these systems invoke international human rights norms and approaches, and whether and how their compliance records differ from their international and national counterparts, are little discussed. Fourth, regional offices of organizations such as UNICEF, the Pan American Health Organization, and WHO are little discussed. We have also neglected agencies such as the European Union's European Centre for Disease Prevention and Control and its African Union counterpart, the Africa Centres for Disease Control and Prevention, which was inaugurated in early 2017. And where organizations, agencies, and partnerships, at whatever level, are discussed, it tends to be as discrete bodies, without deep engagement as to how and why particular human rights law norms and approaches resonated or not in more than one department in any particular organization, or in more than one organization. As a result, we are short on understanding with respect to the messy, competitive context that surely operates within and across key health and human rights actors.

So, the nub of my argument is that our history writing needs to take on new colors—it needs to proliferate in ways that promote law's patina. If we can achieve this, it will create a range of positive outcomes. First, we will help ourselves by learning from the past for the future of health and human rights law. Reflexiveness requires history (preferably, histories that mobilize a genealogical methodology, committed to investigation rather than triumphal reconstruction and alert to the ways in which routine repetitions generate authority). Second, history will help us gauge whether we are dealing with "friend" or "foe" when proponents of global health law praise international human rights law, and the right to health in particular, but call for them to be resized within their new legal field in order to overcome what they see as the obvious deficiencies of human rights law.[24] Finally, histories of health and human rights law and lawyering will help the health and human rights movement, and the human rights movement more broadly, imagine less fraught futures than those conjured by the current, incessant crisis-talk. We know that history is one of the places where a politics of international human rights law is being played out today.[25] Relatedly, we know that history writing is a form of "world making," which intentionally or not, serves certain interests and does disservice to others. It is time for us, as health and human rights lawyers, to investigate our own "world making"—including the limited, almost single-story history we current-

ly have, as well as the histories we could have.

How to proceed? The remainder of this article prescribes two options: first, a history of health and human rights law "favorites," and second, a history of what we have neglected.

Histories of health and human rights law "favorites"

Getting the granularity right will be a challenge, which means it might help to start with what we "know"—namely, access to medicines. We could ask, how have human rights norms and approaches been deployed when claims concerning access to medicines traveled from forum to forum? Can we, for example, draw out how the social and historical density of particular global organizations caused claims to develop different resonances in different places? Put differently, what or who influenced what and whom, in what ways, and with what effects? And while this history of a health and human rights law "favorite" should look at WHO, UNAIDS, the World Trade Organization, and UN human rights treaty bodies, it should also look at the lesser-studied mechanisms—for example, the UN Special Procedures.[26]

These questions about the right to health in the access-to-medicines movement are motivated by the lively literature on the "vernacularization" of rights, which examines how rights travel and how, in so doing, they are transformed and translated, and potentially become transformative too.[27] My questions add to that literature by asking not just how norms and approaches associated with the right to health have traveled from the global to the local (or vice versa), but also about lateral travel from one international organization to another. Is there evidence, for example, that organizations that started with a rights-based approach (such as UNAIDS) have human rights "in their DNA"? And what has been the impact of individual leaders and of dedicated human rights departments within particular organizations? Further, in what ways have "crises," whether internal to the organization or external (for example, a pandemic), affected a formal commitment to rights? Regional organizations should be considered too. How have particular norms and approaches traveled "down" to these organizations from their international counterparts, traveled "up" from particular locals, or traveled across from one regional organization to another? A similar approach could be taken to the growing number of regional networks of cooperation in the health field. And, if possible, the role of management consultants, who have been used extensively by both international and regional organizations, should also be studied. As norms and approaches have traveled (or not) and been transformative (or not), these consultants have been the least visible "translators," and we urgently need to know more about their influence.[28]

There is also the question of when the right to health, or a rights-based approach more broadly, has been translated too far. At times, as noted earlier, health and human rights lawyers have valorized stealth; by this I mean that we have been committed to human rights, but we have also been willing to work with alternatives—from the Millennium Development Goals and development ideas and initiatives more broadly, to universal health coverage. Sometimes these alternatives have come to us packaged as the right to health "by another name," or as a "practical expression" thereof. Equally, sometimes it has been clear that the alternative is meant to avoid human rights in general or part thereof (say, for example, women's rights); and sometimes the claim has been that human rights are not being avoided, just included implicitly rather than mentioned explicitly.

This has been, and is, troublesome terrain, which we need to investigate further. On the one hand, health and human rights lawyers have not pitched rights as the only social justice frame, and being strategic does tend to require nonstandard, even unappealing, choices. On the other hand, synonyms for rights seem to have been used far more in relation to the right to health and other social rights than for civil and political rights. History might help us determine if their continued use will limit opportunities to disseminate, test, and refine norms and approaches associated with the right to

health. Further, as Paul Hunt has explained, where policy makers promote implicit engagement with the right to health or other social rights,

> *it means that only those in authority know whether and when the social right is being taken into account and, if it is, how it is interpreted and applied. Such arbitrariness is inconsistent with the essence of human rights and, indeed, the rule of law.*[29]

Of course, histories of our "stealth" practices will not be able to map this terrain in full, providing a certain guide as to the pros and cons of "rights by another name." But they might identify incontrovertible failures, creating conditions in which we could learn whether translations that go too far have particular markers.

We will also need questions designed to draw out how international and regional organizations have navigated against state resistance to the right to health. The popular view holds that governments—or at least the governments of the most powerful member states—direct these organizations. The advantage of this view is that it constrains naivety about the power of international and regional organizations; the disadvantage is that we may forget to look at how organizations find wiggle room. Here, for example, is Peter Piot explaining that when he was head of UNAIDS, he found "there was space to push the edges of policies that were not popular with many member states, such as gay rights and harm reduction among drug users, and even access to antiretroviral therapy when nearly all high-income countries were opposed to use of development resources for such treatment."[30]

One final set of questions offers another reason why we should commence our histories of health and human rights law "favorites" with a focus on the access-to-medicines movement. This movement has potential to tell us whether international human rights law in general, and health and human rights law in particular, have sloped away from economic inequality. Does the history of access to medicines suggest that one must be either for the market or for the state? Or does it leave space to imagine other options?[31]

Histories of neglect

Of course, some of our history gaps are bigger than others. I call these "omissions," although I recognize that views will differ on what counts as a major omission. I suggest that our guide should be neglect—specifically, what we have neglected regardless of how we date health and human rights law. My list prioritizes the following three omissions. The first is the right to science, which I would describe as widely neglected (although it is now the subject of a draft general comment by the Committee on Economic, Social and Cultural Rights).[32] The second is international law on the life sciences, which is neglected if we discount fleeting references to the UN Declaration on Human Cloning, the Council of Europe's Convention on Human Rights and Biomedicine, and a trilogy of instruments from UNESCO.[33] Lastly, the relationship between health and human rights law and technologies more broadly, including the rise of the "digital welfare state," is also underexplored.[34]

This neglect is surprising and frustrating. I say this, first, because "legal literacy"—by which I mean not more law but a willingness to explore law's capacities—seems essential in countering the popular view which holds that when it comes to new technologies, law either dawdles or moves too soon and, as a result, is best kept out of the picture.[35] And, second, because it has been proposed that big data could help fill statistical gaps, complementing conventional data sources, as the world reaches for Sustainable Development Goal 3, "health for all," which has 13 targets and 27 indicators. Health and human rights lawyers have reason to be skeptical here. Experience with indicators linked to the Millennium Development Goals tells us that numbers speak louder than words and that this can have distorting and damaging effects. Further, as Carmel Williams and Paul Hunt have pointed out, the digital divide between and within countries could become an even greater human rights risk if we turn to big data—data arising from online search queries, web posts, Twitter, and other social media—in the quest to fulfill both Sustainable Development Goal 3 and, more broadly, the call "to leave no one

behind."[36] In my view, it would be a great deal easier to harness health and human rights law instincts of this sort if we had histories that explored our own past engagements with technology.

A related omission also concerns me: what do we know regarding how health and human rights lawyers have conjured what falls outside law? Specifically, how have we shaped non-law through our engagements with both international human rights law and law more generally?[37] How, for example, have we shaped the relationship between international human rights law and ethics? Have we elided ethics and international human rights law, or have we opposed them, sequenced them, or set them apart in some other way? And what effects has this had on how we and others view the capacities of ethics and international human rights law, respectively? These questions are pressing for a range of reasons, not least the increased calls for an ethics of artificial intelligence—calls that rarely make reference to the merits of taking a rights-based approach to this technology.

I am not making a case for hubris among human rights lawyers. But I am suggesting that amid quotidian references to "law and ethics," there is room to reflect on how health and human rights lawyers construct what is within the realm and capacity of international human rights law, and conversely what is not.[38] Reflecting on this should also open up scrutiny of the present passion for an ethics of artificial intelligence (and other approaches such as data justice, data protection, and "responsible research and innovation"), including what might be lost if human rights law were to be sidelined as a governance mechanism and regulatory tool in this field, and what threats and challenges will need to be faced by human rights law if it is called on to engage in this terrain.

Conclusion

I accept that health-and-human-rights-law history writing will not be easy. But it is easy, I think, to understand why these histories are needed. In this article, I have argued that if the past speaks to the future of health and human rights law, and if it is a window into the wider world of international human rights law, we ought to be able to answer affirmatively when asked, "Is there a history of health and human rights law and lawyering?" I have also argued that we ought to begin our history writing by focusing on health and human rights law "favorites"—notably, the right to health and human rights-based approaches to health—but with a commitment that we will also look at what we have neglected, including both the right to science and the relationship between international human rights law and ethics. Of course, whatever the history, the challenge is to get the level of granularity right. And here the article has made one final suggestion: let us begin with what we know best—health and human rights law and lawyering in the access-to-medicines movement.

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UNESCO, International Declaration on Human Genetic Data (2003); UN Declaration on Human Cloning (2005); UNESCO, Universal Declaration on Bioethics and Human Rights (2005).

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