

## What constitutes evidence in human rights-based approaches to health? Learning from lived experiences of maternal and sexual reproductive health

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# What Constitutes Evidence in Human Rights-Based Approaches to Health? Learning from Lived Experiences of Maternal and Sexual Reproductive Health

MAYA UNNITHAN

## Abstract

The impact of human rights interventions on health outcomes is complex, multiple, and difficult to ascertain in the conventional sense of cause and effect. Existing approaches based on probable (experimental and statistical) conclusions from evidence are limited in their ability to capture the impact of rights-based transformations in health. This paper argues that a focus on plausible conclusions from evidence enables policy makers and researchers to take into account the effects of a co-occurrence of multiple factors connected with human rights, including the significant role of “context” and power. Drawing on a subject-near and interpretive (in other words, with regard to meaning) perspective that focuses on the lived experiences of human rights-based interventions, the paper suggests that policy makers and researchers are best served by evidence arrived at through plausible, observational modes of ascertaining impact. Through an examination of what human rights-based interventions mean, based on the experience of their operationalization on the ground in culturally specific maternal and reproductive health care contexts, this paper contributes to an emerging scholarship that seeks to pluralize the concept of evidence and to address the methodological challenges posed by heterogeneous forms of evidence in the context of human rights as applied to health.

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## Introduction

With a focus on applying human rights principles to maximize public health gains, human rights-based frameworks have been drawn on by practitioners, scholars, and activists to compel governments and international organizations to alter conditions of exclusion, deprivation, inequality, marginalization, and discrimination in health.<sup>1</sup> Underlying this attention to human rights-based approaches (HRBAs) is the idea that a lack of respect for human rights impedes the effective reach of public health policies and programs. A human rights focus in public health puts the spotlight not only on who is disadvantaged and who is not but, importantly, on whether a disparity in health outcomes results from an injustice.<sup>2</sup> In so doing, it draws the attention of public health planners and policy makers toward *process* (mechanisms) as much as outcome, and to the workings of *power* (wherein human rights violations represent “pathologies of power” in Paul Farmer’s sense).<sup>3</sup>

To talk of human rights standards as applied to health systems means to focus the attention of governments on (1) maximizing the *availability* of health facilities, goods, and services; (2) ensuring the *accessibility* of these goods, services, and facilities without discrimination; (3) establishing the *acceptability* of services, facilities, and goods in terms of cultural and other forms of appropriateness; and (4) providing medically sound services of the highest *quality* (known as the AAAQ approach to health facilities, goods, services, and programs).<sup>4</sup> The guideline for health governance with regard to human rights is framed by the principles of transparency and accountability and seeks to ensure the participation of affected communities in the design, implementation, monitoring, and evaluation of programs and interventions.<sup>5</sup> The value added by such an HRBA to health is, as Sofia Gruskin and Daniel Tarantola suggest, in the systematization of attention to the issues described above, as well as in the setting of benchmarks to realize them.<sup>6</sup>

The rise of HRBAs to health has occurred at a time of growing skepticism among critical social science scholars about the empty rhetoric of human rights and its neoliberal associations, especially as

applied to developing-country contexts.<sup>7</sup> Interrogating the work of human rights practices and language as a development tool, these scholars question whether HRBAs are effective in redressing social inequalities or whether they in fact serve to reinforce them (insofar as HRBAs become appropriated by elite groups, especially in resource poor settings). Health planners and policy makers who seek to implement human rights-based interventions are also skeptical based on the lack of clearly identifiable evidence of the impact of these interventions in improving health outcomes. Policy makers want to know whether investing resources in HRBAs will have a beneficial impact and seek to carry out impact evaluations accordingly. Impact evaluation refers to

*[an] evaluation of the effects (positive and negative, primary and secondary, short and long-term) produced by a particular intervention, directly or indirectly, intended or unintended. Impact evaluation seeks to attribute impacts, i.e. the effects produced by an intervention and what the effects would have been in the absence of the intervention.*<sup>8</sup>

It is difficult to track the impact of human rights-based interventions in health using conventional measurement methods.<sup>9</sup> This is especially the case given the expectation in planning circles that health policy, like clinical practice, is based on systematically reviewed and critically appraised evidence of effectiveness.<sup>10</sup> HRBAs require additional ways of thinking about what constitutes evidence. This is because human rights are understood, applied, and taken up in a variety of ways by different institutions and individuals, and difficult to capture through the experimental methods of analysis used in clinical trials. Alongside evidence gathered on the basis of observation and controlled experimentation (as in evidence-based medicine), a “subject-near” approach is necessary to ascertain what a human rights-based framework means and achieves. A subject-near approach entails adopting a social, cultural, *interpretive*, and *experiential* perspective.<sup>11</sup> Based on a review of the existing literature and examples of ethnographic work on maternal and sexual reproductive health rights, this article argues against homogenizing tendencies in defining what

constitutes evidence in human rights. Drawing on lived experiences of rights-based interventions in maternal, sexual, and reproductive health in India, I identify ways of thinking about evidence that are underdeveloped within standard experimentally based forms of evidence collection. By examining what human rights mean and how they are operationalized in health care contexts, this paper simultaneously contributes to the emerging scholarship on pluralizing the concept of evidence and addresses the methodological challenges posed by heterogeneous forms of evidence as applied to human rights.

### The framing of evidence in medicine

Modern scientific medicine draws on rigorous, experimentally based statistical methods to establish proof of the safety of therapeutic agents before their introduction into clinical practice. The systematic basis by which interventions are evaluated is part of the mid-20th century shift in medical practice toward a “science-based approach.”<sup>12</sup> Since the 1990s, evidence-based medicine (EBM) has grown from embodying practitioner requirements to embodying a whole raft of procedures within the health sector, including the production of “evidence-based guidelines,” “evidence-based decision making” about old and new treatments, and the promotion of “evidence-based patient choice.”<sup>13</sup> The notion of measurement as applied to human health is based on the idea of biological commensurability—that people can be sorted into standardized groups and populations because their biology is considered to be the same—which, in turn, enables a carefully controlled comparison between treated and non-treated subjects in experimental settings (referred to as random controlled trials, or RCTs).<sup>14</sup>

The evidence from RCTs is considered the most valid because the effects produced by drugs used can be “separated from the background ‘noise’ of placebo effects, biased observers and subjects and chance events.”<sup>15</sup> Further, the approach employed is transparent, enabling inspection by others and thereby promoting accountability.<sup>16</sup> EBM relies on a strict hierarchy of acceptable

evidence linked to clinical effectiveness, largely excluding subjective perceptions.

Nevertheless, EBM’s reliance on RCTs and the epidemiological study of cohorts has been challenged on a number of fronts. Medical practitioners have questioned devaluing the role played by clinical experience and doctors’ expertise. And social scientists criticize RCTs for their inability to capture the complex realities of illness experience (where subjects suffer more than a single ailment, for example), biological variation and cultural influences that exist outside of the controlled environment of experimental trials.<sup>17</sup> Based on an extensive review of the literature critiquing EBM, Helen Lambert identifies six key areas of critical focus, which include the difficulties in generalizing from the effects of interventions on populations into the clinical management of individual cases; the exclusion of experientially informed clinical expertise and judgment; and the failure to incorporate patient knowledge.<sup>18</sup> This chimes with critiques of EBM raised by practitioners who fully recognize the limitations and complexity when it comes to health system interventions.<sup>19</sup>

The issue of considering patient views as part of evidence speaks to a much wider area of debate both within and outside the medical context, which is centered on the question, What counts as evidence? A major critique of EBM by social scientists has rested on the issue of why quantitative forms of evidence count more than qualitative forms, given that human bodies are situated in evolutionary, historical, environmental, social, and cultural contexts.<sup>20</sup> According to Vincanne Adams, eyewitness testimonials, unsystematic reviews, and nonclinical expert accounts (classed as “anecdotal evidence” in EBM) are regarded as less reliable and robust in the evidence hierarchy, compared to statistical and experimentally based models of evidence.<sup>21</sup> Viewed from the perspective of epidemiology, anecdotal evidence does not “say anything valid (ie, reliable) about how to prevent or treat a human health problem ... it is discredited even though it has historically been invested with value in both deciphering ill-health and evaluating clinical outcomes of health

interventions.<sup>22</sup> This is despite the fact that the significance of listening to individuals' personal accounts has been incorporated within EBM in the form of "narrative-based medicine." This "assimilation," Lambert suggests, has been driven by the increasing significance placed on enhancing patients' abilities to make informed choices; yet as an approach, it remains marginal to the mainstream production of evidence in medicine, where the standardization of *qualitative* evidence *within* the confines of an EBM framework has remained problematic.<sup>23</sup> By contrast, narrated stories, anecdotes, folktales, myths, gossip, and rumor are sites where qualitative researchers find evidence of subjective experience—and as I suggest in the next section, they are significant for establishing evidence of the effects of human rights-based interventions.

### Different ways of thinking about rights-related evidence

The critiques of EBM reviewed above are helpful for reflecting on evidence in the context of HRBAs to health. The World Health Organization's recent monograph on the evidence of impact of human rights-based interventions on women's and children's health represents an important milestone in shifting the goalposts for reliable evidence away from a singular focus on *probable* (statistical, experimental) conclusions toward *plausible* ones.<sup>24</sup> The focus on probability is central to EBM: by assigning a probability value that the uncertainty presented by chance factors can be controlled, RCTs are enabled to be more rigorous.<sup>25</sup> Plausibility, on the other hand, is understood to result from assessing a range of sources of evidence that are nonrandom and context-determined (including in a historical and geographical sense).<sup>26</sup> While probability theory is used in the RCT approach to link interventions to outcomes, plausibility-related evidence, as Patrick Kachur suggests, is "assembled from multiple additional indicators ... to support the credible conclusion that the intervention was *delivered sufficiently* and could *reasonably* be interpreted to have caused or contributed to the observed impact" (emphasis added).<sup>27</sup>

Drawing on a case study that evaluates the effectiveness of anti-malarial therapies in Tanzania, Kachur argues that complex public health interventions in particular should not be judged by the same criteria as clinical research (that is, on the basis of experimental evidence). Randomization becomes difficult when there are a large number of variables to control; therefore, Kachur notes that the Tanzanian researchers, in their effort to gauge the effectiveness of combination therapy involving several anti-malarial drugs (as opposed to the standard mono-therapeutic treatment intervention), were best served by evidence arrived at through plausible, observational modes of ascertaining impact. Nevertheless, observational evidence also has its limitations, especially with regard to being more prone to bias (which is removed in experimental research). It is for this reason that observational evidence must always be accompanied by a qualifying set of conditions.<sup>28</sup>

Because a plausibility approach offers the means to capture the effects of a co-occurrence of multiple factors and is more "situated" (in terms of context), it is also more appropriate for evaluating human rights-based interventions. The plausibility approach enables the researcher to "bring people back in" by valuing, for example, indigenous knowledge and lived experiences as bases of evidence.

### *The experience of human rights-based maternal health planning in India*

In 2005, rural health services in India were explicitly organized on the basis of a human rights framework, in the wake of a successful civil society movement to promote and establish the right to information (RTI) that resulted in the 2005 Right to Information Act. That year, the Indian government launched the National Rural Health Mission in 18 states (including 10 high-focus states with the worst health indicators and where in-facility birth coverage was poor). The mission's specific remit was to "undertake architectural correction of the health system to *improve access* to rural people, especially poor women and children to *equitable, affordable, accountable* and effective primary healthcare" (emphasis added).<sup>29</sup> It differed from



previous rural health programs in its explicit focus on enhancing user “rights” to engage in participatory processes and community ownership of local health initiatives, which would be promoted through collaboration between the state and community-based organizations. The collaboration with established health organizations was regarded as promoting the right of rural people to participate in health planning and decision-making about related budgetary allocations.

Human rights-based health planning was regarded by Indian policy makers as critical to addressing the high levels of maternal mortality in the country and in line with the Millennium Development Goals to reduce maternal and infant mortality. (In Rajasthan, one of the focus states where field research was carried out, the maternal mortality ratio was estimated at 388 per 100,000 live births for a population of approximately 60 million people, well above the national figure of 254 per 100,000 live births).<sup>30</sup> In 2006, the government of India launched the Janani Suraksha Yojana (JSY), or “mother protection scheme,” under the National Rural Health Mission as a measure to curtail high maternal mortality. The main focus of the JSY, as distinct from previous programs, was on promoting institutional deliveries through a cash incentive scheme.<sup>31</sup> The principal idea driving the scheme was that a shift in the place of delivery from the home to a health care institution would, in itself, reduce maternal and infant mortality. Cash amounts ranging from Rs 1,400 (approximately US\$31) in rural areas to Rs 1,000 (approximately US\$22) in urban locations were deposited into bank accounts opened by childbearing women.<sup>32</sup>

In July 2009, along with a research team, I undertook a year-long field study in Rajasthan to examine how maternal health rights were understood and operationalized on the ground. The ethnographic study was conducted with local community members, state health workers, public officials, policy makers, and members of 34 civil society voluntary health organizations.<sup>33</sup> Our study found clear oral evidence suggesting that the JSY had been successful in encouraging women to deliver at hospitals rather than at homes. After

the launch of JSY, the number of institutional deliveries rose considerably (from 34% to 60%).<sup>34</sup> These findings corroborate those of a large-scale statistical survey of district-level data that suggest that the introduction of the JSY led to a substantial increase in “in-facility” coverage (that is, of women giving birth in public health facilities) but less of an increase in coverage in terms of antenatal and postpartum care.<sup>35</sup> While the study attributed the “probable reduction in peri-natal and neo-natal deaths” to the increased institutionalization of birth, the researchers were unable to detect an effect on the number of maternal deaths.<sup>36</sup>

This latter finding is also supported by our observations and other qualitative work suggesting that the presumption that delivery in institutions will automatically guarantee maternal and infant safety in childbirth is misleading.<sup>37</sup> In addition, an effect of the scheme in terms of human rights, as concluded by one of the few qualitative studies carried out on the subject, was that the JSY promoted a sense of entitlement to cash rather than the notion of a right to health care per se.<sup>38</sup> Similarly, our study found that the notion of “individual rights” to health care or the idea of the state as being obligated to deliver universal access to health care was barely mentioned by lower class and caste members in the state. So while there was a significant level of “rights talk” and “rights work” involving human-rights based programs among the middle class and caste-dominated civil society organizations, notions of universal human rights (as distinct from indigenous rights) were not evident within poorer and lower caste discourse in Rajasthan.<sup>39</sup> However, given the surge in the mobilization of claims relating to the RTI in urban and rural settings alike, there is a likelihood that individual health-related human rights claims will also emerge from within rural and poorer communities in the near future.

While the Right to Information Act itself has not been invoked to address health violations, the way in which it has instilled an awareness of what rights mean and how they can be deployed for the common good is instructive in shaping an overall understanding of human rights for rights claimants. Public hearings (*jan sunwai*), which emerged

as a key instrument for ensuring accountability within the RTI claims process, could be equally effective in bringing attention to health violations. As recently pointed out by a senior member of an established civil society organization working on health rights:

*[I think] RTIs might prove really useful in working on health budgets and corruption in the field of health. Health issues such as those related to maternal/child deaths, medical negligence, denial of services are issues wherein it doesn't really require much of data and figures but immediate and fair fact findings and investigations.*<sup>40</sup>

The qualitative studies in Rajasthan have provided evidence of how and why rights-based approaches work (or fail) and where institutional and community understandings intersect (or stand apart). Above all, the research highlighted how an understanding of human rights is mediated through social and cultural lenses, as well as the important role played by “context,” which I examine in further detail below.

### Pluralizing forms of evidence in concept, method, and practice

#### *The role of “context” in human rights-based approaches*

Given the significance of “context” in qualitative research, it is important to define what exactly is meant by the term. In the interpretive approach used by anthropologists and sociologists, for example, the term is deployed primarily in a relational sense to situate social relationships within a specific time period (history) with regard to power (politics) and in terms of shared meaning (culture). RCTs do not account for “context” in the same sense, even though they may incorporate process evaluation in their analysis of the effects of an intervention. Drawing on the field study described in the previous section, I will delineate an interpretive, subject-near understanding of context with regard to human rights-related evidence to suggest five different ways in which context-specific interpretations should be taken into account in the production of evidence: (1)

the social or relational, (2) the cultural-moral-ideological, (3) structural power, (4) the experiential, and (5) the historical-processual.

*The social or relational approach to rights:* Observational social science studies demonstrate that rights are not always conceptualized in terms of individual needs and legal entitlements to have those needs met. They also show that rights interventions should account for the effects of indigenous discourses on rights in which rights are socially sanctioned.<sup>41</sup> This perspective has implications for the ways in which we conceptualize community responses to rights and with regard to health systems. In a majority of contemporary indigenous traditions outside the post-enlightenment Anglo-Saxon legal context, rights and entitlements are relationally framed and subject to group decisions. Particularly in the context of reproductive rights in highly patriarchal contexts such as Rajasthan, women’s bodies and reproductive capacities are regarded as publicly “owned,” with decision-making vested in families or other social (kin) groups.<sup>42</sup> The collective group draws on indigenous knowledge (primarily kinship ideologies) to frame the concepts, language, and means through which rights become socially meaningful. In so doing, they set the stage for the types of engagement that community members will have with more universal notions of human rights. To understand the relationship between indigenous conceptions of rights and individual rights (that is, universal rights) to health care, it is therefore important to collect evidence on the social and cultural context of rights.

One of the reasons why the social group is able to determine the extent to which its members have access to health care services and is able to exert influence regarding maternal health seeking is because kinship relations still form the primary means of social support and maternal care in most resource-poor contexts worldwide. It is also important to recognize that kinship ideologies (as a system of ideas governing social relationships) may both limit and promote the realization of universal rights-based approaches and thereby have implications for sexual and reproductive health and

rights. For example, in patriarchal contexts such as in Rajasthan, reproductive health is a favored aspect of women's health, as it serves to continue the patriline, and is therefore a context where women's "individual rights" to maternal health care are collectively sanctioned and enshrined in cultural practice.<sup>43</sup> In other non-reproductive (that is, sexual) contexts, given that men make the decisions, these very same ideologies can serve to deny women rights.

The significance of relational aspects of health is also observed at the level of health systems in the context of task-shifting (redistributing specialist knowledge and activities among health sector workers) to address health-worker shortages.<sup>44</sup> Especially in the context of HIV care, formal task-shifting initiatives have involved the delegation of testing and counseling services to lay health workers and the delegation of antiretroviral therapy services to nurses, as well as the engagement of people living with HIV as "expert patients" who can undertake clinic-based tasks in homes.<sup>45</sup> While this suggests that the views of patients and the expertise of lower level health workers are acknowledged as a way to enhance greater patient participation and choice, evidence linked to the quality of staff relations becomes important for rights-based health care to be realized. This is because, as Karina Kielmann, Fabian Cataldo, and others suggest, the intrinsically hierarchical nature of social division in real-life health systems, the impact of these systems on staff relations, and patient-provider interactions challenge the success of task-shifting strategies and, in turn, the quality of patient care.

*The cultural, moral, and ideological constitution of rights:* The framework of social relations referred to above is grounded in strong ideological and local moral worlds that define social and cultural expectations, responsibilities, and claims related to maternal, sexual, and reproductive care and health. For example, in rural Rajasthan, as in other settings with high maternal mortality rates, the cultural expectation around producing children (often referred to as a woman's "duty") overrides a woman's "right" not to bear children. The idea of *individual*

choice is complex and difficult to isolate in this context, as childbearing is intrinsic to the construction of women's personhood (in a structural sense) and their attainment of full adult social status as mothers and wives. Assertions of universal rights to maternal, sexual, and reproductive health become mediated by these local moral contexts, and any understanding of their impact (or lack thereof) must take such ideological frameworks into account.

*Structural power:* To understand the impact of human rights-based interventions, it is necessary to move beyond community settings to reflect on wider state structures and how these may be connected to systemic processes where discrimination is inherent. Farmer's political economic perspective on health suggests that the poor are most likely to bear the burden of illness, for poverty predisposes individuals to fall ill (as he observed in his work on the social patterns that facilitated the spread of HIV in Haiti in the late 1980s and the 1990s). Farmer uses the term "structural violence" to describe this systemic, social, and economic propensity that leads certain people to fall ill compared to others.<sup>46</sup> Farmer's work is important because it focuses on the structural nature of health abuses. Under this perspective, health issues—rather than being separate from rights—are in fact inextricably intertwined with rights (particularly social and economic rights).<sup>47</sup> Especially among resource-poor families, the quest for better health is often hidden within a broader struggle for economic gain.

The struggle for better livelihoods also locates the relationship between health and human rights in an everyday context of illness and social suffering.<sup>48</sup> A focus on including more routine struggles for survival within mechanisms for health care rights evaluation enables everyday practices of hierarchy, discrimination, and power to be taken into account. Class discrimination permeates health care settings not only in Rajasthan but also in states like Tamil Nadu that boast the best maternal health indicators; in both of these settings, poor women are mistreated, given less attention and medication, and rendered "bioavailable" for state family planning programs.<sup>49</sup> The fact that caste and class are



compounded in denying poor women their human rights, including their right to health, demonstrates the absence of a level playing field, which needs to be accounted for in the production of evidence.

*Experiential approach to assessing the effect of human rights-based interventions in health:* As we learn in the context of alternative therapies, evidence includes not only relief from physical symptoms but also the meaning of the illness experience, how the body-self connection may be reconstituted through therapy, and the effects on the patient's identity in the healing process. If bodily experience is central to the patient's evaluation of the success of a therapy, then evidence of the therapy's success, as Christine Barry argues using data from homeopathic patients' modes of constructing effectiveness, is in its effect on understanding as much as on bodies.<sup>50</sup> The experiential, embodied, inter-subjective, and phenomenological aspects of healing—while considered acceptable evidence in interpretive disciplines such as anthropology—are not accounted for in clinical research.<sup>51</sup>

Non-biomedical systems of healing evoke a relational sense of context in their premise that the remedial therapeutic effect resides “inside an energetic system that comprises the patient, the remedy, the healer and the setting.”<sup>52</sup> As demonstrated in the research on infertility in Rajasthan, local healers are considered efficacious because they are perceived to be able to alleviate conditions of “social death” and stigma, and the loss of a moral sense of self associated with the disruption of social relations that accompany infertility.<sup>53</sup> Local healers deliver an experience of care that is appropriate to the cultural understanding of the body as a lived entity. Accordingly, the bodily experience of health interventions (violent or otherwise) needs to be taken into account in human rights-based forms of evidence.

*Historical-processual:* It is important to capture the historical and processual impacts of rights-based interventions (such as shifts in responses to health right interventions), which are neglected in the context of experimentally based impact evidence.<sup>54</sup> The fact that human rights interventions in health

are evaluated by users in the context of their previous experiences with the health system has an important effect on the reception and impact of these interventions as positive or negative. For example, the “cafeteria” approach to contraception (where a variety of options, such as pills, condoms, and intrauterine devices, are provided) as a means of enhancing choice in India's maternal health program needs to be reconsidered in light of the previous coercive contraceptive policies promoting female tubectomy as part of India's family planning program in the 1980s. The experience for rural and poor women targeted by the state's family planning program was one of overwhelming coercion, often involving forced sterilization. In this historical context, the provision of “choice” has been received with skepticism by many—a point further reinforced by the fact that neither intrauterine devices nor condoms have been popular. Ironically, sterilization has remained the main preferred method of contraception by health workers and women alike (albeit by women who have met their desired family composition).

### *Implications for methods*

The importance of “context” in evaluating the effects of rights-based approaches to health, as suggested above, requires rethinking standard (statistical, experimental) methods of producing evidence. It urges us to focus on research methods that are conducted in everyday settings and to pay particular attention to the contextual features of interaction and related meaning-making. Certain kinds of qualitative approaches, such as the ethnographic and deliberative, especially lend themselves to this task.

Ethnographic research is the collection of evidence through personal and individual ways of knowing, rather than through standardization and randomization, and involves the co-construction of knowledge in the interaction between the researcher and respondent. It is a space where the researcher's emotions, intuitions, relations with others, bodily ways of knowing, and self-reflection on these intersect with those of the respondent (drawing on a phenomenological paradigm).<sup>55</sup> Unlike most other

qualitative approaches, ethnographic research collects information on meaning as well as practice, recognizing that there can be a difference between what people say or think they ought to do and what they actually do. Real-life interactions are recorded (in which patients and healers construct meaning together) as a means to capture understandings of efficacy at the intersections of the individual/collective, institutional/informal, and local/global. At the same time, value is given to the importance of individual experience in the sense that a specific interaction between healer and patient is taken into account, bringing individual circumstances to bear on the production of evidence. Rather than the production of an overarching singular form of evidence, the premise in this form of interaction is that a different piece of evidence is produced each time.<sup>56</sup> Learning from the lived experience of meaningful health care relations requires the acknowledgment of an “assemblage” of evidence much in the way that Aihwa Ong and Steven Collier use the term to illustrate how differently juxtaposed domains of politics, technology, and ethics define new material collective discursive relations.<sup>57</sup>

It is important to note that a common critique of experientially informed data, as discussed above, has to do with the data’s reliability, for some informants are more willing than others to share their experience. To counter this criticism, ethnographers talk to a range of people in a systematic way to capture both the “silences” and what is spoken across the social spectrum of, for example, class, gender and sexual orientation, age, political affiliation, geographic location, and religious connection. In addition, time-based variations are accounted for through the observation of processes such as life-course events and rituals, which are also occasions when the social aspects of rights become materially tangible. Such methods enable tracking the impact of HRBAs in terms of how they change actors’ opportunity structures and participation over time. Similarly, methods that capture experiential knowledge—such as illness narratives, health-worker case studies, accounts of health-seeking, and birth histories within medical institutions—are equally salient for gathering evi-

dence of the impact of human rights-based health interventions.<sup>58</sup>

Other emerging forms of ethnographic methods—such as global ethnography, which focuses on capturing flows of ideas and information across different discursive levels—are also pertinent to assembling human rights-related evidence.<sup>59</sup> This kind of new “de-territorialized ethnography,” as undertaken by Sally Engle Merry in her study of transnational movements against gender violence, “studies place-less phenomena in a place, small interstices in global processes where decisions are made, tracks global information flows and marks the points at which competing discourses intersect in the myriad links between global and local conceptions and institutions.”<sup>60</sup> Similarly framed, the field-based research on maternal health and human rights-based planning in India found that on-the-ground human rights interventions in health became tangible through the “rights work” of an array of differently positioned actors: state policy makers and planners, health providers, lawyers, health and legal rights activists, and scholars. Such work, in turn, was dependent on how these actors perceived rights and on the political and socio-cultural conditions that enabled them to effectively mobilize their understanding of health rights.<sup>61</sup> For example, feminist and legal health activists deployed the narrative of domestic violence and the Protection of Women against Domestic Violence Act of 2005 as a means to gain reproductive rights for women on the ground.<sup>62</sup> And different groups of legal activists at the local and national levels invoked different legal instruments (including international human rights conventions and Indian constitutional law) to hold the state accountable on various issues (such as preventing maternal death and guaranteeing rights in the marital residence). The broad range of what constitutes human rights-based work is also key to understanding why it is so hard to evaluate the impact of such work. This does not mean that it is not possible, but that the practice of evaluation itself needs to be more broadly based and plurally framed.

Other methods, such as “deliberative methods” originating within the political sciences, may

be of particular significance in gathering plural forms of data on evidence.<sup>63</sup> Compared to other group and participatory methods, they are more specifically focused on the element of deliberation (the act of considering different points of view and coming to a reasoned decision) in terms of problem solving. According to Julia Abelson et al., deliberative methods represent an approach “which allows individuals with different backgrounds, interests and values to listen, understand, potentially persuade and ultimately come to more reasoned, informed and public-spirited decisions.”<sup>64</sup> As a more legitimate means of involving the public and patients in decisions affecting them than existing participation methods, deliberative methods are emerging as practical aids to decision-makers tackling challenging public policy issues that require a range of evidentiary inputs. An example of this is the *jan sunwai* (public hearing) in India, as discussed above, which is a deliberative process used by the state to gain evidence of people’s experience invoking the rights to health, employment, and information.

If consistency, comparability, and transferability are regarded as the core criteria of robust and reliable evidence in public health, then a major challenge arising from plural forms of evidence is the issue of how comparable and transferable the evidence is from one context to another. However, as demonstrated in the discussion above, the transferability of ethnographic data is possible at the level of contextually grounded evidence, such as in the ways in which kinship norms restrict or promote reproductive rights across India and the rest of the world. The challenge of managing diversity can be met within a framework where diverse qualitatively based evidence is pulled together as an “assemblage.”

In determining appropriate methods for gathering evidence for the plausibility of an impact (as opposed to evidence for the probability of an impact), it may be useful to distinguish between the different uses to which this evidence is put, whether for easily discernible clinical interventions or for human rights-related interventions. This observation resonates with the point made by Lambert about the ends served by the evidence, allowing for a distinction between an *evidence for* (use in clinical

interventions) versus an *evidence of* (the impact of rights, in this case).<sup>65</sup>

## Conclusion

The causal forces driving human rights-based health outcomes are multiple and difficult to map in a conventional sense (of cause and effect). This is because human rights are not simply discrete legal instruments but concepts whose meaning is interpretive, relationally constituted, experientially based, and historically shaped. This makes the evidence of the impact of rights interventions on health outcomes more complex to track than through experimental paradigms of evaluation alone. What is needed is an approach that moves beyond a view of evidence that is grounded solely in its standardized use in medicine and toward pluralist, epistemological interpretations of evidence and methodological diversity.

When viewed in terms of the evidence hierarchy, these plural forms of evidence (including observational studies, lay people’s perceptions and accounts, patients’ individual narratives, collective assessments, and historical and ethnographic case studies) are perceived as less reliable and robust. And yet given the abundance of these non-experimental forms of evidence, particularly in the case of evaluating HRBAs to health, I suggest resituating the frame of evidence such that experience and epistemological diversity are not erased in the search for what is considered “most robust” by the standards of EBM.<sup>66</sup> Health planners and policy makers who seek contextually informed evidence on the impact of human rights-based interventions on health will find that, as discussed in the paper, the effectiveness of human rights-based interventions cannot be measured by experimental standards of evidence alone.

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