

## Commentary

### Bioethics, Human Rights, and Childbirth

#### JOANNA N. ERDMAN

The global reproductive justice community has turned its attention to the abuse and disrespect that many women suffer during facility-based childbirth. In 2014, the World Health Organization released a statement on the issue, endorsed by more than 80 civil society and health professional organizations worldwide. The statement acknowledges a growing body of research that shows widespread patterns of women's mistreatment during labor and delivery—physical and verbal abuse, neglect and abandonment, humiliation and punishment, coerced and forced care—in a range of health facilities from basic rural health centers to tertiary care hospitals. Moreover, the statement characterizes this mistreatment as a human rights violation. It affirms: "Every woman has the right to the highest attainable standard of health, which includes the right to dignified, respectful health care throughout pregnancy and childbirth." The WHO statement and the strong endorsement of it mark a critical turn in global maternal rights advocacy. It is a turn from the public health world of systems and resources in preventing mortality to the intimate clinical setting of patient and provider in ensuring respectful care.

A focus on women's experiences of abuse and disrespect during facility-based childbirth opens new opportunities for maternal rights advocacy, including an engagement with bioethics. There is a large literature on bioethics and childbirth, but because it has tended to focus on micro-ethical conflicts within patient-provider relations and the use of new technology in clinical settings, it was of little relevance to human rights in safe motherhood, which was traditionally concerned with public health policies and programs to reduce maternal death.<sup>3</sup> The move of maternal rights advocacy into the clinical setting creates an opportunity to link bioethics and human rights in multiple ways.

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Competing interests: None declared.

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This commentary takes this opportunity by applying the sociological critique of principle-based analysis in bioethics to the emergent field of human rights in childbirth. Following a brief account of the turn in global maternal rights advocacy towards abuse and disrespect in facility-based childbirth, the commentary explores principle-based analysis, a method of human rights reasoning dominant in the field. Principle-based analysis is also an influential analytical method in bioethics, but one subject to a strong sociological critique for its abstract universalism, that is, its failure to attend to the lived experience of an ethical encounter and to the institutional structures and social relations which give rise to it. Drawing on this critique, the commentary uses the rich sociological literature on what social science theories and methods can offer bioethical analysis to build a way forward for human rights advocacy in maternal care. It does so by identifying three main features of a sociological approach in bioethics—attention to lived experience, institutional culture, and structural injustice-and by outlining the advantages of these features for a human rights analysis of abuse and disrespect in facility delivery.

#### Human rights in facility-based childbirth

Beginning in 1987, the Safe Motherhood Initiative brought attention to the gross global inequity of maternal death. The Initiative reframed the issue from one of human tragedy to human failure by emphasizing that most maternal deaths could be averted by ensuring access to skilled birth attendance and emergency obstetric care, both often addressed by encouraging women to deliver in health facilities. By the mid-1990s, this human failure was recast as a human rights violation. It was widely acknowledged that under international law, women have an enforceable right to survive pregnancy and childbirth. Human rights in safe motherhood drove a new era of advocacy. The UN

Human Rights Council issued historic resolutions on maternal mortality and human rights.<sup>6</sup> The UN Special Rapporteur on the right to health highlighted maternal mortality in a series of reports.<sup>7</sup> Reproductive justice advocates litigated cases under regional and UN human rights treaties in efforts to enforce these rights.<sup>8</sup>

In 2011, for the first time, a human rights treaty body held a national government accountable under international law for a preventable maternal death. The case, Alyne da Silva Pimentel Teixeira v. Brazil, involved a Brazilian woman of African descent who died as a result of obstetric complications while seeking care in multiple health facilities.9 The UN Committee on the Elimination of Discrimination against Women, which considered the case, found that Brazil had failed to ensure "appropriate services in connection with pregnancy, confinement and the post-natal period" in violation of the rights to life, health, and non-discrimination.10 The case is especially significant for its broad definition of quality of care. The rights violations involved more than technical breaches of clinical standards; rather, the Committee also focused on the neglect and discrimination that characterize the experience of poor Afro-Brazilian women in seeking facilitybased maternity care. The Committee emphasized the indignity of being forced to travel from one hospital to another in search of care, only to be left to die unattended in a makeshift area of a hospital hallway.

In this respect, the case reflects an important shift in maternal rights advocacy. Global research on abuse and disrespect in facility-based childbirth has grown in recent years, revealing a widespread phenomenon. Women continue to die in childbirth because of how they are treated in facilities during labor and delivery, or because they are driven away from facilities for fear of mistreatment. Attention in advocacy has thus shifted beyond ensuring facility delivery to ensuring its quality of care, and moreover, to a conception of quality beyond

technical and clinical competence to respectful and humane treatment. Such concerns are not new or novel, at least for countries with longer histories of facility-based birth. In the US, Ladies' Home Journal published an article in 1959 entitled Cruelty in Maternity Wards that detailed inhumane treatment almost identical to that reported worldwide today.<sup>12</sup> Until the last decade or so, there was little literature addressing the subject on a global level, which was at best described as an emerging problem.<sup>13</sup> Researchers, however, began to systematically document abuse and disrespect in facility-based childbirth, and a global movement formed that, much like its predecessor, uses international human rights law to advocate for change.

The 2011 charter Respectful Maternity Care: The Universal Rights of Childbearing Women is an illustrative example.14 Drafted by the White Ribbon Alliance, a global network of maternal health advocates, the Charter seeks to expand the concept of safe motherhood beyond the prevention of death and disability, and the human rights analysis beyond a right of access to health services. In citing the right to health, the Charter emphasizes dimensions of dignity, respect, non-coercion, and non-discrimination in health care delivery.15 It also leans heavily on traditional civil and political rights, such as rights to liberty and security of the person, and freedoms from cruel, inhumane, and degrading treatment; interference with privacy; arbitrary detention; and discrimination.<sup>16</sup> Within the health and human rights field, the concept of human rights in patient care reflects this emergent mode of analysis, that is, the application of human rights norms in patient care settings, particularly in patient-provider interactions.17 It has brought new interests and actors into the field, including the UN Special Rapporteur on Torture, who issued a 2013 report on torture and ill-treatment in health care settings, including the mistreatment of women seeking reproductive health care.18

# Principle-based analysis in bioethics and human rights

A focus on human rights in health care settings also

opens the opportunity to engage with bioethics. One site of engagement is the shared dominance of principle-based analysis in bioethics and human rights. In simplest terms, this philosophically based, abstract mode of reasoning in bioethics involves the assessment of facts against universal moral principles.<sup>19</sup> Human rights analysis tends to work through a complementary set of principles, which are formally articulated in international law and once invoked against a set of facts tend to end rather than drive normative deliberation. Human rights standards serve as both the interpretive categories and the evaluative norms by which conduct is assessed.20 This tendency is clear in human rights analysis focused on abuse and disrespect in childbirth. One of the earliest studies on the subject, conducted at referral-level hospitals in the Dominican Republic, uses two columns to visually represent its human rights analysis.21 The first column lists "norms of dignified care." These include prohibitions on routine episiotomy (surgical enlargement of the vaginal opening) and pushing on the uterus to hasten delivery, and mandates to put baby to breast immediately and to offer counseling on postpartum family planning. The second column records how often these norms are followed, a frequent entry being "never." The study thus concludes: "There was no privacy, no dignity and no attempt to honor the human and reproductive rights of the laboring women."22 Abuse and disrespect in childbirth, and the human rights violations they represent, are defined by a measure of norm deviation. Health services research has largely followed this method, focused on categorizing conduct (abuse, coercion, indignity, discrimination, abandonment, detention) against human rights principles (liberty, equality, transparency, accountability, dignity) with the normative conclusion thus assumed.<sup>23</sup> Human rights reports also share this methodology. A seminal report on maternity care in Kenyan health facilities documents observed practice against formal legal norms, and labels the deviations as human rights violations.24

The impulse of this analytical method is understandable, even laudable. Bioethical and

human rights principles set normative expectations that abuse and disrespect in the health care system is wrong and should not be tolerated. Moreover, they do so precisely by an authoritative claim to abstract universalism. Yet such absolutism leads to a distancing from, even misunderstanding of the very subject the analysis seeks to elucidate: the experience of abuse and disrespect in childbirth. When individual experience of mistreatment is strictly categorized and made meaningful against a prescribed norm, its analytical significance is inhibited. The categories come to define the experience itself. Consider vaginal examination in labor, which is used by providers to assess cervical dilatation and effacement, fetal head position, and membrane status, but which is also often practiced routinely without informed consent, and thereby analyzed as a violation of the human rights norm of bodily integrity.<sup>25</sup> Yet an ethnographic study on the transition to hospital birth among rural migrant women in Bolivia revealed that for many women the indignity of the vaginal examination was the public spectacle of it: dislike and fear of having to display one's genitals under a collective male gaze.26 The human rights violation of routinized or unnecessary vaginal examination need not stem from a breach of bodily or personal integrity. It may and is often experienced as both. The critical point is that the experience of abuse and disrespect with respect to any maternal care practice may be voiced across rights categories or through none at all, but an analytical method must be sufficiently open to capture its varied nature.

Against this critique, human rights analysis sometimes seeks to capture the more nuanced human quality of rights violations through first person narratives that describe the sound of a slap, the hurt of humiliation and the pain of punishment. These efforts to particularize the experience, however, risk a different shortcoming. They risk stripping an act, a practice, or an experience of its context, and thus of the myriad forces that define it and give it meaning. Analysis focused on the immediacy of a single act, its victim and perpetrator, risks obscuring the structural injustices that breed abuse and disrespect in health care, thereby hiding

their social, political, and economic origins.<sup>27</sup>

## A sociological approach to human rights in childbirth

These concerns about the abstract and universalistic qualities of principle-based analysis are well voiced in a large and critical literature that speaks to the contributions of social science theories and methods for bioethical engagement.<sup>28</sup> Rather than work from abstract universalism, a sociological approach in bioethics works from particularity and context. It engages with the interpersonal relations, the institutional structures, and the normative patterns of the social world from which violations emerge, and which construct the morality they reveal. As articulated by José López, sociological insight 'refurbishes' the ethical enterprise, not necessarily by abandoning its norms but by discovering their meaning through empirically rich and structurally informed analysis.29 In this respect, the sociological approach shares much with other critical approaches in bioethics, especially feminist bioethics, which have long registered concern with the limitations of principlism.30 Moreover, the sociological approach is not entirely unknown to the field of abuse and disrespect in childbirth. Lynn Freedman and colleagues recently reported on a methodology to define disrespect and abuse in childbirth in projects on respectful maternity care in Kenya and Tanzania.31 Their approach starts precisely from "where women live and labour" and seeks to give concrete meaning to human rights standards in the field over time and through attention to women's lived experiences of abuse and disrespect.32 In other words, the starting point of analysis is not the abstract principle applied to experience, but the experience itself. In a compelling articulation of this idea, Arthur Kleinman explains that the social sciences can "deeply humanize ... [ethical engagement] by allowing variation and pluralism and the constraints of social position to emerge and receive their due, so that ethical standards are not imposed in an alien and authoritarian way but, rather, are actualised as the outcome of ... engagement across different worlds of experience."33

The remainder of this commentary draws on the sociological critique in bioethics to offer a way forward for human rights advocacy in maternal care. It does so by identifying three main features of a sociological approach in bioethics—attention to lived experience, institutional culture, and structural injustice—and outlines the advantages of these features for a human rights analysis of abuse and disrespect in facility delivery.

A critical feature of a sociological approach is an interest in how people make meaning of lived experience. There is no empirical truth to a human rights norm or its violation, only the embodied experience of it. Human rights violations, the very definition of abuse and disrespect in childbirth, are thus morally less certain. The meaning women give to particular aspects of childbirth is likely to differ across social locations and sometimes in contradictory ways. Yet this seems a necessary consequence of privileging women's experiences in their variation and even in their discrepancy.34 In this respect, the approach is truly iterative. The normative standard retains some regulative function, but experience is not simply subsumed under it, but comes to define it over time.

A good example of this approach can be seen in feminist social science analysis of over-medicalized childbirth, defined by excessive or inappropriate medical interventions such as labor induction, fetal monitoring, and Caesarean section.35 Where autonomy is privileged as an abstract governing norm, over-medicalization is presented as a loss of control for women through the pathologizing of pregnancy as a site of risk and conflict.<sup>36</sup> Women feel duty-bound to act in the best interests of their child, now equated with patient obedience and acquiescence in recommended interventions. Yet there are counter and conflicting interpretations of this interaction.<sup>37</sup> Some women use the medical management of childbirth in empowering ways, appropriating it to their own ends. For example, women may give control to medical authorities as a means to divert blame for birth complications or negative outcomes, or to get some rest, knowing that otherwise they will be expected to continue their household duties late into term or to resume them

soon after birth.38 Framing over-medicalization through an abstract norm of autonomy ignores or minimizes these values of security and rest, values which may reflect not simply individual preference, but differences among women in social location and resources.39 Consider also the diverse ways in which over-medicalization may exercise control over women. One study, for example, explains how routine use of fetal monitors devalues or dismisses women by replacing their embodied experiences of labor with an objective, expert measure of its progress.40 This gathering and keeping of information can be a profound abuse of power, cruel in its arbitrariness. In research on facility-based childbirth, women describe being at the mercy of providers, waiting without explanation and fearful of being abandoned within medicalized systems they do not understand.41 Contrary to intuition, then, over-medicalization can harm women and constitute a human rights violation as much through neglect and abandonment as coercion or intrusion. A sociological approach thus inverts the human rights analysis. Rather than subsume individual experience under a human rights norm, it seeks to construct the content of that norm from the particulars of experience. A richer concept of autonomy in medicalized care is constructed from a fuller appreciation of different women's different needs in labor and delivery.

A second feature of a sociological approach is its attention to institutional culture through which patients and providers must interact and ultimately negotiate power.42 The term "in facility" does not merely locate the place of mistreatment, but identifies a set of norms, hierarchies, and conventions through which acts of abuse and disrespect are rationalized, even normalized. This is why mere legal sanction rarely dislodges systemic mistreatment. Legal rules are read through and subordinated to a system of medical authority.<sup>43</sup> The Special Rapporteur on Torture expressly recognizes this unique challenge in stopping torture and ill treatment in health care settings, noting the routine defense of practices on "grounds of administrative efficiency, behavior modification or medical necessity."44 These same justifications are invoked against claims of mistreatment in facility-based childbirth.<sup>45</sup> Providers regard themselves as entitled, even obligated to use harmful practices to ensure healthy deliveries. Many of these practices, however, are clinically unnecessary, based in tradition rather than evidence, and practiced for provider convenience rather than patient benefit.<sup>46</sup> Medical authority can thus foster a culture of impunity, where human rights violations do not only go unremedied, but unnoticed.

A sociologically informed rights-based approach does not dismiss biomedical authority, but checks its commanding influence. Human rights are mechanisms of accountability, used to open authoritative institutions like medicine, and to challenge their entrenched hierarchies of power.<sup>47</sup> Human rights operate as a kind of counter-discourse to relocate patients and their authority within this institutional culture, to mediate their relationships with providers.48 Thinking about human rights in this way, Alicia Ely Yamin contends, "underscores how rights ... are not self-standing truths, but loci of contestation over power."49 They introduce new forms of argument and evidence into an otherwise closed institutional setting. This is the very same mission of bioethics, at least in its beginnings. Born alongside American rights movements in the 1960s, bioethics was a challenge to medical institutional power. A sociological approach continues to challenge, yet not from a competing perch of expert authority. It begins and proceeds from lived local experience, anticipating and working the fault lines of institutional power relations.

These fault lines are most likely to be found in the deeper societal structures that lie behind and give force to human rights violations in maternity care, that is, the macro-context. This is the third feature of a sociological approach: the capacity to step back from the local setting of a violation and ask about the broader power dynamics that sustain it, give it meaning, and make it a predictable rather than anomalous event. Studying the patterns of abuse and disrespect in childbirth inevitably uncovers structural injustice, precisely because health systems are social institutions. <sup>50</sup> A health system wears the inequalities of the society in which it functions.

The same is true of institutional maternity care, which reflects markers of social advantage and disadvantage, lines of social inclusion and exclusion, and re-inscribes them onto laboring and delivering women.<sup>51</sup>

An early study on nurses' abuse of patients in obstetric public health services in the Western Cape Province of South Africa has profoundly influenced the field, precisely because it draws the link between individual action and historical and structural conditions in answering the question: Why do nurses abuse patients?52 The study reaches into the history of the nursing profession within black communities in South Africa, the construction of the nurse identity and the socialization of nurse training, both of which served to distance African nurses from their patients, one group of women tasked with the 'moral uplifting' of another.53 The study uses this historical viewpoint to explain the discriminatory character of much abuse in facility delivery, how ideologies of patient inferioritythose in need of control and discipline, those undeserving of care and respect-track lines of social disadvantage, primarily poverty and youth. This is a very different way to read gender, race, and class within a human rights analysis. That is, not as individual attributes but as structuring relations of power within facility-based practice.

Locating maternity care within particular historical, cultural, and societal settings also opens opportunities for structural change. The focus on abuse and disrespect in facility-based childbirth offers a new language for maternal rights advocacy, and a means to connect with larger social movements seeking systemic reform. An example is a recent midwifery campaign in Mexico around 'obstetric violence,' language expressly chosen to situate abuse and disrespect in childbirth within a generalized pattern of violence and social inequality, especially as related to gender, race, and class.<sup>54</sup> The campaign's goal is to show how the treatment of women in maternity care facilities mirrors their treatment in society at large: in the home, in the street, and in schools.55 By drawing a connection between obstetric violence and violence in other realms of everyday life, these advocates seek to join

a national conversation on state accountability and violence in Mexican society.

The sociological critique of bioethics calls for something radical, a reconstruction of the very enterprise of ethical analysis. It calls on social science theories and methods to enlarge the sites of inquiry, the categories of analysis, and the strategies of intervention. It perhaps evens calls bioethics back to a tradition of addressing health within the clinical setting as part of a larger project in social justice. The learning from a sociological critique of bioethics is equally applicable in the field of human rights. As global maternal rights advocacy moves inside facilities and the patient-provider encounter, a sociological approach offers a way forward for human rights analysis. It offers a way for advocates to work toward transformative social change in the intimate spaces of patient care.

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