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## **Peer-Reviewed CME Article**

**Structural Competency and Reproductive Health** 211  
Margaret Mary Downey and Anu Manchikanti Gómez

## **Global Reproductive Health Care Ethics in the 21st Century**

### **From the Editor**

**Reproduction, Inequality, and Technology: The Face of Global Reproductive Health Ethics in the Twenty-First Century** 224  
Ashish Premkumar

### **Ethics Cases**

**Is Lower Quality Clinical Care Ethically Justifiable for Patients Residing in Areas with Infrastructure Deficits?** 228  
Commentary by Marcia C. Inhorn and Pasquale Patrizio

**How Should Trainees Respond in Situations of Obstetric Violence?** 238  
Commentary by Nicholas Rubashkin and Nicole Minckas

### **Podcast**

**What Clinicians Can Do to Address Maternal Mortality in the US: An Interview with Dorothy Roberts, Nadia Sawicki, and Dr. Stacie Geller**

### **The Code Says**

**The AMA Code of Medical Ethics' Opinions Related to Global Reproductive Health** 247  
Scott Schweikart

### **Medical Education**

**Linking Global Health to Local Health within an Ob/Gyn Residency Program** 253  
Sara Whetstone and Meg Autry

<b>State of the Art and Science</b>	
<b>Balancing Demand for Universally Improved Health Outcomes with     Need for a Local Standard of Care</b>	<b>261</b>
Christina Krudy and Kavita Shah Arora	
<b>Policy Forum</b>	
<b>Why Crisis Pregnancy Centers Are Legal but Unethical</b>	<b>269</b>
Amy G. Bryant and Jonas J. Swartz	
<b>Who Counts? What Counts? Place and the Limits of Perinatal     Mortality Measures</b>	<b>278</b>
Claire Wendland	
<b>Medicine and Society</b>	
<b>When Should Screening and Surveillance Be Used During Pregnancy?</b>	<b>288</b>
Nancy D. Campbell	
<b>Second Thoughts</b>	
<b>Should Race be Used as a Variable in Research on Preterm Birth?</b>	<b>296</b>
Kacey Y. Eichelberger, Julianna G. Alson, and Kemi M. Doll	
<b>About the Contributors</b>	<b>303</b>

## PEER-REVIEWED CME ARTICLE: ORIGINAL RESEARCH

### Structural Competency and Reproductive Health

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*Editor's Note: To claim one AMA PRA Category 1 Credit™ for the CME activity associated with this article, you must do the following: (1) read this article in its entirety, (2) answer at least 80 percent of the quiz questions correctly, and (3) complete an evaluation. The quiz, evaluation, and form for claiming AMA PRA Category 1 Credit™ are available through the [AMA Education Center](#).*

#### Abstract

Reproductive health disparities—particularly those experienced by racial and ethnic minority groups—are considered a persistent public health issue in the United States. Frameworks that focus on social determinants of health seek to identify the forces producing these disparities, particularly social conditions that create vulnerability to premature death and disease. Such frameworks pose challenges to health care provision, as structural factors can seem immutable to health care professionals trained to treat individual patients. Here, we discuss the links between reproductive health disparities and social determinants of health. We then apply to reproductive health care the *structural competency* framework, developed by physician-scholars to encourage health care professionals to address health disparities by analyzing and intervening upon sociopolitical forces.

#### Introduction

The World Health Organization (WHO) defines reproductive health as an integral component of complete well-being, noting that reproductive health indicates that people “have a responsible, satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so” as well as access to “safe, effective, affordable and acceptable methods of fertility regulation” [1]. Reproductive health care’s success in advancing this vision is mixed [2, 3], suggested by persistent [reproductive health disparities](#) in the US, particularly with respect to race, gender, and socioeconomic status. Women of color and low-income women fare worse than their white and higher-income counterparts in nearly every aspect of reproductive health, including access to prenatal care [4], maternal mortality [5], cervical cancer mortality [6], sexually transmitted infections [7, 8], access to services (including assisted reproductive technologies) [2], and education [4].

For clinicians trained to treat individual patients, the structural underpinnings of these reproductive health disparities pose practical and conceptual challenges. *Structural competency* is a framework developed by physician-scholars that seeks to address these challenges and to encourage health care professionals to recognize, analyze, and intervene upon the structural factors that impact health disparities. Here, we define “structural” factors as those that codify, in systems like medicine, law, or welfare, differential access to social, political, and economic opportunities [9]. Structural factors produce group-differentiated vulnerabilities to harm, including health disparities, as well as group-differentiated access to goods, services, and resources [10]. In response to persistent reproductive health inequities and to challenges reproductive health professionals face in adequately engaging the social determinants of health, this paper applies structural competency to reproductive health care.

### **The Social Determinants of Reproductive Health**

No single factor accounts for the persistent reproductive health disparities in the US. Major health organizations, such as the Centers for Disease Control and Prevention (CDC) and the WHO, have embraced social determinants of health as an explanatory framework to highlight the role of unequal social conditions in creating and perpetuating avoidable differences in health [11, 12]. These social conditions include those created by laws, policies, and practices overseeing “where persons work, live, learn, and play” [13], such as those regulating health care professionals and wider spheres (e.g., zoning, educational systems, food access, courts, and labor markets) [14]. The CDC states that familiarity with social determinants of health data can help practitioners better recognize “root causes” [15], which health care professionals can miss if they only rely upon individual-level assessment and interventions [16]. Amidst calls for health care institutions to play a role in eliminating reproductive health disparities and in incorporating social determinants of health into practice [17], scholars argue that reproductive health care operates within paradigms that directly and indirectly create or exacerbate reproductive health disparities [2, 3, 18, 19].

These paradigms impede access to care and reify disparities for many women by limiting patient autonomy, perpetuating stereotypes about marginalized groups, and undergirding negative health care experiences that might curtail future health care seeking [2, 20]. Consider *Madrigal v Quilligan*, a 1978 federal class action lawsuit brought forward by Latina women coercively sterilized in a Los Angeles public hospital. A former medical student testified that Dr. Quilligan, the named defendant under whom she trained, connected poverty, overpopulation, and social benefits of racialized sterilization. Quoting Dr. Quilligan, Gutiérrez writes “poor minority women in Los Angeles County ‘were having too many babies,’ that this was placing a ‘strain on society,’ and that it was ‘socially desirable’ that the women be sterilized” [21]. Here, public health policies underlay the connections between individual patient characteristics (e.g., being Mexican, low income) and the perceived social danger of overpopulation. Beyond *Quilligan*,

examples of health care practices and policies that replicate reproductive oppression and impede care for many women include the twentieth century's [forced sterilization](#) of poor and working-class women, disabled women, and women of color [22] and the coercive sterilization of at least 148 women in California prisons between 2006 and 2010 [23]; long-acting reversible contraception (LARC) promotion targeting racial or ethnic minority and poor women without regard for the ways that this might invoke population control [3]; and state family cap policies that deny cash benefits to children born in families already receiving benefits [24].

### **Structural Competency as a Response to the Challenges of Addressing Reproductive Health Disparities**

What should reproductive health care professionals take from these examples of reproductive oppression? First, reproductive health care professionals must realize that their field has played a role in exacerbating health disparities by serving as gatekeeper to services, resources, and technologies that facilitate or constrain reproductive choice [25]. These practices are not matters of individual bias or failure or of health care professionals acting as “bad apples” [14, 26]. Rather, the medicalization of wider social problems (e.g., poverty, racism, nationalism) vividly emerges in reproductive health care [27]. The (potentially) pregnant body is a site of systematized and heightened regulation and [surveillance](#), particularly when those bodies are poor, disabled, immigrant, minority, and so on [27]. The medicalization of social problems has ethical implications for reproductive health care professionals, who must balance their pursuit of patient care and respect for patient autonomy, justice, beneficence, and nonmaleficence with the realities of institutional and structural discrimination experienced by patients. Indeed, research indicates that health care professionals do not feel equipped to understand or intervene upon structural factors, despite acknowledging the impact such factors have on their profession [28, 29]. Trained to treat individuals, reproductive health care professionals might contribute to the replication of problematic health care trends by ignoring structural barriers to care [30] because they and their institutions lack the skills and resources to identify, analyze, and imagine structural interventions.

*Structural competency*, an emerging paradigm in health care, seeks to address medicine's overemphasis on the individual (e.g., biology, behaviors, characteristics) while addressing the hierarchies that produce unjust health conditions. Structural competency responds to dominant paradigms in health care education that neglect the ways in which access to the resources needed to make health changes and choices are influenced by unjust [social determinants](#) such as the differential treatment patients receive from health care institutions and professionals with respect to race, class, or immigration status, for example [31]. Developed by physician-scholars, structural competency is a means not only to analyze structural factors that impact health disparities but also to operationalize health care interventions to reduce health disparities, including in reproductive health [13, 32, 33]. Structural competency moves beyond cultural competency, which can

reinforce racial, ethnic, linguistic, or other stereotypes by positioning these cultural groups as unsophisticated subjects and professionals as sophisticated or objective [34]. Structural competency offers a means to pursue ethical practice in a context of structurally produced health disparities without blaming the individual for health outcomes produced by upstream social conditions that are ultimately beyond his or her control.

Universities and clinics across the US have engaged with structural competency, offering conferences, trainings, and semester-long programs [28, 35]. A shift to structural competency is ultimately a hopeful one. To health care professionals, the social determinants of health can feel immutable; structural competency helps demystify health's causal pathways and identify systematic ways to help patients.

### **Applying Structural Competency to Reproductive Health**

Structural competency has particular utility in politically charged settings such as reproductive health care, where the day-to-day activities of health care professionals are highly sensitive to changes in the social, political, and economic spheres. Successfully treating patients while navigating these rapidly changing conditions requires understanding of the structures shaping these conditions. Metzl and Hansen outline five core elements of structural competency generally: defining clinical interactions in structural terms, developing an extra-clinical language of structure, rearticulating "cultural" presentations in structural terms, observing and imagining structural intervention, and developing structural humility [14]. Here, we apply these elements to reproductive health care.

*Recognizing the structures that shape clinical interactions.* Structural competency holds that recognition of structures shaping clinical interactions—including laws, funding mechanisms, and markets—is important, as it allows health care professionals to understand the wider spheres governing their clinical work. With that understanding, health care professionals can identify and correct missed opportunities to support their patients in navigating structural barriers to care. Abortion counseling services provide an instructive example of the structures shaping clinical interactions and their implications for health care and outcomes [31]. Owing to targeted state legislation that drains clinic budgets by forcing compliance with regulations beyond what is needed for patient health and safety [32, 33], many abortion clinics must meet patient need in minimal time. In turn, clinics cut services such as in-depth counseling, which provides space for patients to process their values and preferences related to abortion [36]. Furthermore, in-depth counseling can enhance quality of and access to care when it identifies structural barriers to health outcomes (for example, difficulties travelling to follow-up appointments among undocumented persons due to police checkpoints) [36]. A structurally competent approach to abortion care, incorporated into education and training curricula, would provide health care professionals with a framework to understand and analyze the social

and political conditions that constrain the types of care available and influence clinical outcomes.

*Developing an extra-clinical language of structure.* An extra-clinical language of structure refers to incorporating terms and concepts from social, political, and economic theory into the health care encounter. Consider the case of promotion of LARC to prevent adolescent pregnancy. Although adolescent pregnancy is now recognized to be influenced by a complex set of factors—including education, housing, and employment—that pregnancy prevention alone cannot solve [37], Higgins argues that promoting LARC as if contraceptive efficacy were a panacea to structural barriers faced by young, poor women of color is unfair to patients and health professionals alike because it puts the onus on individual patients and professionals to solve a problem better addressed by more robust funding of education, housing, and employment programs [37]. In this context, language engaging social conditions (e.g., poverty) is ineffectual and does not reach the level of extra-clinical language suggested by structural competency, given that these arguments are not informed by the rich discussions of structural barriers in social, political, and economic theory. Drawing on structural competency, health care professionals might see how the absence of structural factors and social well-being in discussion of LARC locates the origin of social problems in the reproduction of poor adolescents. They could then be ready to discuss contraceptive decision making with their patients (and colleagues) in terms that go beyond clinical effectiveness, which is commonly promoted by physicians as the most important contraceptive consideration for women, although women often consider other aspects such as acceptability, values, and autonomy to be of equal or greater importance [30, 38]. A structurally competent perspective surfaces the ways that social inequities with respect to race, gender, class, and age are reproduced within clinical settings and in rhetoric about LARC, highlighting the need for alternative counseling approaches (such as shared decision-making models, which seek maximum patient input and use patient-directed language) [31].

*Rearticulating “cultural” presentations in structural terms.* Rearticulating “cultural” presentations in structural terms refers to understanding the structural factors producing differential clinical outcomes and presentations based on race or ethnicity and including these factors in any assessment and treatment plan. Health care professionals must consider the ways in which their knowledge base (e.g., research studies that refer to young, poor, or minority women as “at risk” for pregnancy and that replicate moralizing risk discourses [39]) and their professional norms explicitly and implicitly stratify women’s fertility based on stereotypes that are often framed as inherent to group “culture” [40]. One example is the stereotype that young, poor women of color are at risk for unintended pregnancy due to the controversial notion of a “culture of poverty” [41, 42] or “cycle of poverty” [43] that devalues education and other means of social mobility and promotes promiscuity. In rearticulating “cultural” presentations, health care

professionals should analyze how patients' decisions, feelings, and resources related to reproductive health might be influenced by differential opportunities to parent and exercise autonomy over childbearing options. Rearticulating cultural presentations in structural terms enables health care professionals to [recognize stereotypes](#) when they emerge in practice and to treat patients' issues more accurately and acceptably [31].

*Observing and imagining structural intervention.* Observing and imagining structural interventions means health care professionals are both *aware* of key examples of thinking beyond the individual and *capable* of envisioning how they might apply them in practice. Reproductive health professionals can look to the past, present, and future to observe and imagine structural interventions. Women of color launched the reproductive justice movement in 1994, because they were dissatisfied with the reproductive rights movement's narrow focus on "choice." They openly challenged the exclusion of abortion access from health care reform and pushed for an intersectional understanding of reproductive oppression, particularly the forces that denied women of color the human right to have children and to parent with safety and dignity, as well as the right not to have children [44]. These activists paved the way for minority women's leadership in health advocacy and in organizing successful campaigns against unjust policies and practices [45]. One example of reproductive justice in action is Black Women Birthing Justice, a San Francisco Bay Area collective that seeks to ensure, for black women, the right to birth with safety and autonomy—where, how, and with whom they choose. This organization works closely with local health providers and grassroots community groups to expand access to the range of pregnancy and postpartum care options for black women (e.g., Medicaid coverage of home birth, access to doulas and midwives of color, and access to trauma-informed, strengths-based breastfeeding support) as well as to increase the accountability of medical institutions to black pregnant women through community accountability boards [46].

In the current political climate, health care professionals might consider structural interventions such as training in how to resist collaboration with US Immigration and Customs Enforcement (ICE) and other policing institutions within their own clinics and at community-led direct actions [47, 48]. For example, citing erosion of community safety and public trust in local institutions, Planned Parenthood Mar Monte in California was one of 18 signers of a letter demanding that the Fresno sheriff immediately end a partnership between ICE and the police department, which had facilitated detainment and deportation proceedings of over 100 people [47]. Detainment and deportation can worsen reproductive health outcomes (e.g., increased risk for unintended pregnancy and sexually transmitted infections) by depriving patients of necessary reproductive care as well as subjecting undocumented women and families to disproportionate state violence and surveillance, thereby constraining their reproductive choices and experiences [49, 50]. Reproductive health care professionals might also consider following the example of movements such as [White Coats for Black Lives](#), which leverages clinicians' professional

privilege to galvanize political support for the Black Lives Matter movement [51]. The Black Lives Matter movement and reproductive health equity are inextricable, given that police brutality and surveillance can be understood in the words of one physician as “particularly extreme forms of maternal stress” and might influence black women’s health outcomes or childbearing decisions [48]. As the political climate surrounding reproductive health intensifies, professionals are in a privileged position to advocate for structural interventions addressing not only the immediate reproductive health care needs of their patients but also the conditions that produce differential vulnerabilities in the first place. Structural competency allows for more appropriate interventions by aiding clinicians in recognizing and responding to the most salient structural contexts in the clinical encounter itself while also motivating clinicians and their health care systems to intervene in the extra-clinical determinants of health.

*Developing structural humility.* Structural humility is the capacity of health care professionals to appreciate that their role is not to surmount oppressive structures but rather to understand knowledge and practice gaps vis-à-vis structures, partner with other stakeholders to fill these gaps, and engage in self-reflection throughout these processes. Self-reflection allows health care professionals to better discern how structures are impacting them and their patients and identify systematic ways to help patients. By definition, structural issues cannot be addressed by an individual. Health care knowledge and interventions will always be partial. Engaging with this reality rather than clinging to professional status and expertise means that professionals will be better able to capture the complexity of their own experience as well as that of patients and other allies.

Although necessary, increased awareness of structural influences on health through more robust education and training will only take reproductive health professionals so far. Collective, coalition-based action to create lasting structural changes must follow reflection and awareness raising [14]. One example is taking a collaborative, movement-based approach to reform, such as the movement for single-payer health care [52, 53]. Reproductive health care professionals are well poised to argue for full access to reproductive health care (including abortion) in legislation that expands health care delivery [54], which would address social determinants of reproductive health by lowering financial barriers to the full-range of health care options patients need to achieve reproductive autonomy. In order to be fully visible and influential, they must do so alongside other health care professionals and advocacy groups such as Physicians for a National Health Program or National Nurses United [53]. Embracing structural humility, reproductive health care professionals must be careful not to dominate discussions or strategy at the expense of other stakeholders but rather cooperate and compromise as they move into spaces where multiple knowledges, identities, and priorities converge.

## Conclusion

Structural competency represents a powerful framework for shifting the burden of eliminating health inequities from individual professionals and patients to institutions and systems, including health care, schools, and clinics. Structural competency training with a reproductive health focus might improve clinician sensitivity to social determinants of health, encourage generative self-reflection, and open opportunities for solidarity with patients. It might help health care professionals offer safer, more acceptable, and therefore more effective care. Given that reproductive health care professionals may work within “beleaguered” systems [55], structural competency is a means to empower these professionals to face occupational difficulties and organize for transformative change [56]. Because changes in structure cannot be achieved by individuals alone, structurally competent reproductive health care will take collective force, skill, and imagination but can ultimately play a key role in helping health care professionals to advance a vision of reproductive health as part of complete community well-being, to the benefit of patients and professionals alike.

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## FROM THE EDITOR

### Reproduction, Inequality, and Technology: The Face of Global Reproductive Health Ethics in the Twenty-First Century

Global reproductive health has seen a paradigm shift since the turn of the twenty-first century. Although initially focused in the 1980s on a global reduction in maternal mortality through access to trained practitioners in connection with the Safe Motherhood Initiative [1], the field has quickly moved into new terrain. Now, global reproductive health attends to new issues, such as the use of assisted reproductive technologies (ARTs), as well as new manifestations of older problems, such as the effects of emerging infectious disease like Zika and Ebola on perinatal health [2]. The bioethics of reproductive health is no exception; innovations in theory and practice have arisen in a dynamic biomedical landscape. With the fluidity of movement of disease and technology due to global economics and the gradual breakdown of nation-state borders, there is no longer a split between the domestic and the international; the local is global, and vice versa [3-5].

Yet the elephant in the room when it comes to global reproductive health care and bioethics has to do with inequality [6]. Health resources and technologies—and the geospatial movement required to access them—have consistently been a target of analysis by biomedical researchers and bioethicists alike [7]. However, other questions of inequality—particularly as it relates to its incorporation into research methodology, medical education, and health policy—have yet to be the subject of a cohesive bioethical analysis that takes into consideration the important changes in reproductive health over the past 20 years [2]. The recent election of President Donald J. Trump has signaled a reification of a conservative political agenda, both on the global and domestic scale; whether by curbing access to or funding of abortion-related services or limiting the role of transgender people in the military, sexual and reproductive health are once again at the fore of political, bioethical, and popular discussion [8].

If people across the world require reproductive health services as a fulfillment of their reproductive rights, then how has this goal gone astray? [9]. How can a bioethical perspective unveil hidden inequalities in the construction of global reproductive health as a field? And, ultimately, how can practitioners use bioethics to improve care and education of caregivers in settings of structural violence? This issue of the *AMA Journal of Ethics* explores the complex ethical environment of global reproductive health with a focus on “local” aspects of reproductive health inequalities to ask crucial questions about

how the global health landscape can evolve to provide high-quality reproductive health care in the twenty-first century.

One ethics case considers the complex role of ARTs in global health. Marcia C. Inhorn and Pasquale Patrizio examine a case of provision of [low-cost but less effective ARTs](#) in rural areas of Lebanon, where low-intensity civil conflict continues in the wake of the Syrian refugee crisis of 2013. Arguing that standards of care for infertility will need to vary with resources and sociopolitical context, they contend that by reaffirming a human right to fertility, funding and other resources can be used to improve technology and access to infertility services.

Two articles discuss bioethical issues concerning medical education in the area of global reproductive health. Nicholas Rubashkin and Nicole Minckas respond to a case of a medical student rotating abroad who witnesses an episode of "[obstetric violence](#)" [10], broadly defined as the intentional "appropriation of the body and reproductive processes of women by health personnel" [11]. Rubashkin and Minckas consider the student's moral distress and options for intervening as well as the ethical underpinnings of those options. Importantly, they argue that educational institutions have an obligation to support students who witness obstetric violence and to prepare them for rotating abroad. And Sara Whetstone and Meg Autry discuss an [educational curriculum](#) for resident physicians with both a didactic and an experiential component that focuses on the provision of reproductive care in low-resource settings locally and globally.

Three articles focus squarely on Western biomedicine, with attention to unique policy issues in the United States. Amy G. Bryant and Jonas J. Swartz focus on the problem of [crisis pregnancy centers](#) (CPCs), or nonprofit, pseudo-clinical organizations that claim to provide perinatal health services but instead serve as vehicles for anti-abortion counseling [12]. Bryant and Swartz argue that even if some CPCs are technically legal, they are unethical entities because they purport to offer medical services when, in fact, they do not offer a full-range of care options or perspectives. Examining illicit opioid use during pregnancy, Nancy D. Campbell shows how, historically, the medicalization of maternity and criminalization of addiction have served to expand [biomedical surveillance](#) of drug-using pregnant women. She argues that in the age of evidence-based medicine, biomedical surveillance should only be conducted to provide quality care and in accordance with the principles of nonmaleficence and respect for patient autonomy. And Margaret Mary Downey and Anu Manchikanti Gomez show how physicians can use the framework of "[structural competency](#)" to analyze and seek to change social structures that contribute to health disparities.

Finally, three articles look at the crucial issue of research in reproductive health, arguing for a more nuanced approach to understanding structural violence against pregnant women. Claire Wendland examines the use of [perinatal statistics](#) in Malawi and the

United States, focusing primarily on the ethical bias towards hospital births for which statistics on perinatal mortality are readily available. Specifically, she demonstrates that the focus on perinatal health indicators by both policymakers and clinicians obscures factors that are critical to maternal and child health, such as the quality and the sociopolitical context of care. Christina Krudy and Kavita Shah Arora examine the contradictory findings of two [clinical trials on antenatal corticosteroids](#) for reduction of perinatal morbidity in the setting of preterm delivery, one conducted in low- and middle-income countries and the other in the US, to highlight the need for understanding of cultural and health care contexts when extrapolating study findings. And Kacey Y. Eichelberger, Julianna G. Alson, and Kemi M. Doll examine the long-standing problem of incorporating [race as a variable](#) in studies of preterm birth outcomes. They argue that when race is used as a categorical variable in research, it should be understood not as a genetic or biological construct, but rather as a biosocial concept—as an “approximation of the complex historical and ongoing lived experience of systematic, institutionalized discrimination.”

In this month’s [podcast](#), interviews with Dorothy Roberts, Nadia Sawicki, and Stacie Geller further illuminate the much higher rates of maternal mortality among black women than white women in the United States [13]. This phenomenon argues for a more thorough evaluation of health care services and appropriate statistical methodology to adequately capture cases [13]. While Roberts illuminates the historical context behind the numbers, Sawicki examines ethical tensions between maternal and child health, particularly “fetal consequentialism”—the idea that the birth of a healthy baby outweighs potential harm to the mother. Finally, Stacie Geller discusses what clinicians, policymakers, and students can do to rectify inequalities and improve maternal outcomes in the US.

All of the scholars who have contributed to this month’s issue of *AMA Journal of Ethics* take a critical stance towards reproductive health in the global and local setting by focusing attention on the sociohistorical, economic, political, and gendered contours of quandaries in both research and clinical practice. Whether by re-evaluating obstetric violence in Argentina or considering the opioid epidemic in the United States, the need for a decisive review of the bioethics of reproductive health lies at the heart of this issue. Especially in our current political climate, I hope that this collection of papers will start conversations and drive debates on the need for a holistic, bioethically situated approach to reproductive health.

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## ETHICS CASE

### Is Lower Quality Clinical Care Ethically Justifiable for Patients Residing in Areas with Infrastructure Deficits?

Commentary by Marcia C. Inhorn, PhD, MPH, and Pasquale Patrizio, MD, MBE

#### Abstract

Reproductive health services, including infertility care, are important in countries with infrastructure deficits, such as Lebanon, which now hosts more than one million Syrian refugees. Islamic prohibitions on child adoption and third-party reproductive assistance (donor eggs, sperm, embryos, and surrogacy) mean that most Muslim couples must turn to in vitro fertilization (IVF) and intracytoplasmic sperm injection (ICSI) to overcome their childlessness. Attempts to bring low-cost IVF-ICSI to underserved populations might help infertile couples where no other services are available. However, a low-cost IVF-ICSI protocol for male infertility remains technically challenging and thus may result in two standards of clinical care. Nonetheless, low-cost IVF-ICSI represents a form of reproductive justice in settings with infrastructure deficits and is clearly better than no treatment at all.

#### Case

Dr. Moussa, a reproductive endocrinologist and infertility specialist, has arrived in Lebanon. Although he is a native of Beirut, the capital city, he has spent much of his life training and working in the United States. Now a well-known specialist, he is sponsored by a university in Lebanon to consult about how best to treat infertility across the country. Specifically, Dr. Moussa is discussing in vitro fertilization (IVF) plus direct injection of sperm into an egg, a method called in vitro fertilization plus intracytoplasmic sperm injection (IVF-ICSI). His team in the United States has developed an IVF-ICSI protocol that can be done in a mobile laboratory.

Meeting with fellow clinicians in Beirut, Dr. Moussa begins, "As you know, Lebanon is known for having high rates of male-factor infertility and for having a large number of IVF clinics. Many of those clinics and laboratories are clustered in Beirut [1-3], where we have dedicated electricity with no interruptions in service and state-of-the-art procedure rooms for oocyte retrieval. Here it's easy to get patients the clinic care and lab services they need. But high rates of male-factor infertility are also here," he points on a map to towns in the Beka'a Valley, east of Beirut and near the border with Syria. This area has limited and frequent interruptions in electricity supply, limited road access, and, due to

influx of Syrian refugees since 2012, significant civil and political instability [4]. “Together,” Dr. Moussa continues, “via mobile laboratory, we could bring IVF-ICSI to the patients in the Beka’a Valley who can’t get to us and our labs in Beirut. The only drawback is that the rates of IVF-ICSI success are lower when done in the mobile laboratories than when done in the Beirut-based laboratories [5]. I think you’ll agree, however, that it’s better than these patients having no access at all to IVF-ICSI.”

“I’m not sure I do agree,” said one member of the group. “I have many more questions about how this would work and whether it’s ethical to have two different standards of care, based on the quality of the lab service.”

### Commentary

Reproductive health services, including infertility care, are important in countries with infrastructure deficits. Such is the case of Lebanon, a country that experienced 25 years of civil war and occupation (from 1975 to 2000), and is now facing a new crisis—namely, the influx of more than one million Syrian refugees fleeing from the civil war in their home country [6]. Dr. Moussa is rightfully concerned about the dearth of health care facilities in Lebanon’s Beka’a Valley, where more than 350,000 refugees are now living along the border [7].

Dr. Moussa’s recommendation for low-cost [assisted reproductive technologies](#) (ARTs) is in keeping with the 1948 United Nations (UN) Universal Declaration of Human Rights, Article 16:1, which states: “Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family” [8]. Furthermore, in 2001, the World Health Organization (WHO) meeting titled “Medical, Ethical and Social Aspects of Assisted Reproduction” [9] recommended that “infertility should be recognized as a public health issue worldwide, including in developing countries,” and that “research is needed on innovative, low-cost ART procedures that provide safe, effective, acceptable and affordable treatment for infertility” [10]. Although neither document discusses the mode and type of delivery of infertility care in conflict zones, both the UN and the WHO specify the positive right to fertility, including in developing nations. The UN further specifies that this right is irrespective of race, nationality, or religion [8]. Thus, Dr. Moussa’s call to develop a low-cost IVF-ICSI program in the Beka’a Valley is reflective of ethical principles developed by the world’s leading international health and social justice organizations. Furthermore, such a program has the humanitarian goal of addressing refugee reproductive health services in the now-conjoined Syrian-Lebanese conflict [6].

However, if Dr. Moussa brings a mobile, low-cost IVF-ICSI program to the Beka’a Valley, the standard of care, as reflected in clinical pregnancy success rates, will possibly be lower than in Beirut’s well-established IVF clinics. Thus, the ethical dilemma of two standards of IVF-ICSI care is a crucial sticking point for his program.

Dr. Moussa's argument, however, is ethically sound: namely, lower-quality IVF-ICSI care is better than no care at all. By virtue of its low-cost and portability, a mobile IVF-ICSI protocol would bring with it the possibility of overcoming infertility among those whose chances are otherwise nonexistent. IVF-ICSI works through direct injection of a spermatozoon into a human oocyte, facilitating fertilization and leading to the potential creation of a human embryo. With IVF-ICSI, even azoospermic men who have no evidence of sperm in their ejaculate can father a biogenetically related child if sperm are produced in and retrieved from their testicles. Because the program is offered at low cost, IVF-ICSI cycles can also be repeated, thus increasing the chances for success. This program is especially important for underserved populations, including refugee populations, whose desire and need for children may be high, given all that they have lost [11].

The ultimate goal of the low-cost IVF-ICSI program is to establish effective, safe, and affordable treatment, thereby representing a form of reproductive justice. This goal is especially critical in the Muslim world, where other paths to parenthood, including third-party reproductive assistance and child adoption, are generally not available [12-14]. In Muslim-majority countries, the medical treatment of infertility is thus vital, since it is the only way for most infertile Muslim couples to become parents [13].

### **Islam, Male Infertility, and Moral Opposition to Sperm Donation**

As a native of Lebanon, Dr. Moussa is likely aware of the particular religious and moral sensibilities that make treatment of infertility through ART especially crucial. Across most of the Sunni Muslim world, which encompasses about 87-90 percent of the world's Muslim population [15], child adoption is not religiously condoned as a legal path to parenthood [12]. Similarly, third-party reproductive assistance—either through egg donation, sperm donation, embryo donation, or gestational surrogacy—is considered *haram*, or religiously forbidden [13]. Although third-party reproductive assistance, especially egg donation, has been approved through religious *fatwa* decrees issued by some of the most prominent Shia Muslim clerics, including in Lebanon, sperm donation has been rejected by all but one Shia ayatollah in Iran [14]. This is because knowing one's *nasab*, or exact genealogy or lineage, is considered a moral imperative in Islam. Thus, sperm donation causes genealogical "mixture" or "confusion" and unknown paternity. Sperm donation resulting in unknown paternity is considered religiously immoral in most Muslim societies, which are organized patrilineally (i.e., individuals' kinship belonging, inheritance rights, and family names are all conferred through the father's side of the family). Given this religious opposition to sperm donation, infertile Muslim men in Lebanon, whether Sunni or Shia, are usually extremely unwilling to consider sperm donation as a solution to their infertility [16].

Infertile Lebanese Muslim men reject this option on four moral grounds. First, sperm donation destroys a child's *nasab*, or genealogy, which is considered unjust to the donor child and harmful to the child's psychology. Second, such a child of unknown paternity is considered to be *walad il-zina*, or literally a "son of sin" (i.e., a bastard). Most Muslim men are clear that a *walad il-zina* "won't be my son" [17]. Third, using donor sperm—and introducing that sperm into a wife's womb—is tantamount to *zina*, or adultery. Even though no illicit "touch or gaze" occurs in donor insemination, most Muslim men consider intrauterine donor insemination to be a major violation of marital trust, destroying the sexual intimacy of the conjugal relationship [16]. Finally, Muslim men fear the potential for incest, if the offspring of an anonymous sperm donor unintentionally meet and marry later in life [13, 14, 16].

Dr. Moussa likely realizes that most Muslim men will never consider the relatively simple and low-cost technique of donor insemination to overcome their infertility, but he is also aware of the fact that male infertility is one of the most common infertility problems presenting to Middle Eastern IVF clinics (60-90 percent of cases) [16]. Male infertility cases in Lebanon and other Middle Eastern countries are usually genetic in nature; they often cluster in families and are linked to cultural practices of consanguineous (cousin) marriage [18]. As a result, these genetic cases of male infertility are often severe, involving very low sperm count and motility, poor morphology, and nonobstructive azoospermia [16]. Because most genetic problems of male infertility do not respond to standard treatments (hormones, other medications, or behavioral therapies), IVF-ICSI is the only hope for fatherhood among most infertile Muslim men, given their opposition to sperm donation.

### **IVF-ICSI and Its Challenges**

*Effectiveness.* Like any form of assisted reproduction, IVF-ICSI cannot guarantee a pregnancy [16]. Even under the best conditions, IVF-ICSI might not succeed on the first attempt, thus requiring costly repetition. IVF-ICSI is also highly dependent upon the hormonal stimulation and extraction of healthy oocytes from women's bodies. Whereas the fertility potential of older men can often be enhanced through IVF-ICSI [13], women's fertility is highly age sensitive, with oocyte quality declining at later stages of the reproductive life cycle. Finally, when it does succeed, IVF-ICSI may be perpetuating genetic defects into future generations. In those rare instances in which male infertility is due to microdeletions of the Y chromosome, these and other genetic disorders can be passed by IVF-ICSI to male offspring. The [ethics of passing genetic mutations](#) to children has been an increasing cause for concern [19].

*Cost and access.* Dr. Moussa appears to be particularly concerned about IVF-ICSI costs and problems of access in Lebanon. Although Beirut is home to a number of high-functioning and high-performing IVF clinics, it is an expensive city, and most IVF clinics there are privately owned and operated [16]. In 2002, a single cycle of IVF could start at

US\$1,272 and exceed a global average (excluding the US) of US\$3,500 per cycle [20]. In a country where 70 percent of the population generates an annual income of less than US\$10,000, according to World Bank data [21], affording IVF-ICSI is difficult for most Lebanese couples, who often deem it a “last resort” when no other solution can be found [16]. For the destitute Syrian refugee population now living on the Lebanese-Syrian border, obtaining IVF-ICSI may be virtually impossible due to the cost of treatment and the 77-kilometer distance to Beirut. Reliable forms of public transportation are limited and costly, and travel is now risky because of crumbling infrastructure and random acts of political violence.

### **The Low-Cost IVF (LCIVF) Movement**

Dr. Moussa is thus proposing a brave solution—namely, bringing a mobile IVF-ICSI clinic and laboratory to the Beka’a Valley. In doing so, he likely intends to make Lebanon a part of the growing global movement for low-cost IVF (LCIVF). LCIVF has emerged over the past decade, with many initiatives being proposed to help couples who cannot afford treatment [2]. Its goal is to make safe, affordable, effective IVF accessible to all of those who need it, primarily infertile couples living in resource-poor settings like Lebanon.

One example of such an initiative is the nonprofit organization, headquartered in Belgium, called the Walking Egg. Founded by IVF clinician-activist Willem Ombelet, the Walking Egg was one of the first to develop a transportable LCIVF laboratory system [22], significantly reducing the cost of IVF [22]. Clinical success rates with the Walking Egg system have exceeded 30 percent [23]. However, other attempts to create LCIVF protocols have failed to yield such promising results [5]. Thus, even if Dr. Moussa and his Beirut colleagues are able to transport the low-cost IVF-ICSI protocol to the Beka’a Valley, it is uncertain what percentage of patients can actually be helped by this low-cost method.

A major problem is that low-cost IVF-ICSI is more technically demanding than LCIVF alone. IVF-ICSI requires a micromanipulator with a high-powered microscope, a micro-injector, and skilled embryologists who are able to inject spermatozoa into oocytes under controlled laboratory conditions. Thus, to date, no reliable low-cost IVF-ICSI method has been developed [2]. Indeed, Dr. Moussa’s low-cost IVF-ICSI protocol might have limited efficacy in solving most of the male infertility cases that he would encounter in the Beka’a Valley.

### **The Two Standards of Care Dilemma**

Dr. Moussa is ethically justified in his belief that overcoming at least some cases of male infertility is better than overcoming no cases at all. Put another way, he is arguing that a lower quality of clinical infertility care is ethically justifiable. Why? On the one hand, infertility is not a life-threatening condition, wherein low-quality care could cost the life of the individual patient. Furthermore, the quality of patient care delivered to poor

infertile couples in the Beka'a Valley can remain high, even if the success rates of treatment remain low. If using a cheaper and simpler IVF-ICSI protocol would be an improvement over the total absence of treatment in the resource-poor, infrastructure-challenged Beka'a region, then it is not morally wrong for Dr. Moussa to recommend this protocol to patients. Without Dr. Moussa and his team, such patients would have no other way of accessing care and overcoming their infertility problems.

Furthermore, as part of this low-cost protocol, patients would receive infertility diagnoses and a better understanding of the medical nature of their infertility conditions. This knowledge, in and of itself, can be empowering. In the Middle Eastern region, the medicalization of male infertility has helped to diminish one cause of its stigma—namely, the mistaken conflation of infertility with impotence [13, 16]. Increased awareness of male infertility has led to its growing recognition as a medical problem to be treated [16].

Finally, a low-cost IVF-ICSI program would be welcomed with open arms in the Beka'a Valley. Most pious Muslim couples there likely consider medical conditions such as infertility to be God given, and they also believe that God creates solutions such as IVF-ICSI to overcome their suffering [24]. Thus, infertile Muslim couples are often active in seeking medical solutions [13]. By locating a mobile program on the Lebanese-Syrian border, Dr. Moussa and his team could provide relief to thousands of childless Muslim couples who have otherwise been living under stress and uncertainty.

Nevertheless, Dr. Moussa is questioned by his fellow clinicians in Beirut about whether providing two standards of care is ethical. Because the low-cost IVF-ICSI program would be delivered to poor Lebanese and Syrian refugee patients, who are unable to pay for better services or to access those services within a conflict zone, it might provide false hope to a population that has already suffered tremendously. As with any reproductive treatment, proper [informed consent](#) should be put in place to fully explain the possible limitations of the treatment provided by the mobile IVF-ICSI protocol. Properly executed informed consent procedures should help patients exercise their autonomy in choosing a treatment and should include clarification that treatment might not succeed.

### **Infertility and Health Disparities**

The two-standards-of-care dilemma is not found in Lebanon alone. Dr. Moussa has spent most of his life as a medical student and clinician in the US, where health care services have never been distributed equitably. In the case of infertility services, most poor and minority Americans, including resettled Arab refugee couples living in areas of concentrated poverty, have much less access to IVF-ICSI than educated white couples, even in the 15 US "mandate states" where IVF is either fully or partially [covered by health insurance](#) [11]. As of 2003, it was estimated that only 24 percent of North Americans' ART needs were being met [25]. Many infertile Americans cannot begin to

afford treatment given that the average gross cost of a single IVF cycle in 2006 was 50 percent of annual disposable income, the highest in the world [26]. Furthermore, it took until January 2017 for the US government to begin to provide affordable IVF-ICSI services to US military veterans, including those who had served and were severely injured in the US-led wars in Iraq and Afghanistan [27].

These disparities in access to effective treatment for infertility are unjust and reflect substantial economic, racial, ethnic, and geographic disparities [28]. Such infertility treatment disparities are receiving increasing attention from the ethics committee of the American Society for Reproductive Medicine [29]. In addition, a growing movement in North America, called Friends of Low-Cost IVF, is calling for more affordable IVF in an effort to expand access [2].

### **Conclusion**

One conception of distributive justice suggests that saving lives takes priority over creating lives; the needs of the many should take precedence over those of the few. When resources are limited, elective care for nonlife-threatening conditions such as infertility is a low priority on the overall resource-allocation scale. Nonetheless, infertility treatment disparities *are* unjust. When such disparities are present, reproductive justice dictates that some infertility treatment is better than no treatment at all.

Overcoming infertility through low-cost IVF-ICSI is a small step in the right direction, even in societies such as Lebanon, with its infrastructure deficits and growing Syrian refugee crisis. Sadly, infertility treatment disparities in Lebanon will persist until (a) the tragic Syrian civil war ends, (b) the refugee crisis abates, (c) American troops are withdrawn from the Middle East region, and (d) peace prevails across this troubled land [11].

Perhaps when the aforementioned conditions are met, Syrian refugees will be able to return home to IVF-ICSI services in their own country. Poor infertile Lebanese couples from the Beka'a Valley will also be able to make their way safely to Beirut, where excellent, state-of-the-art IVF facilities already exist [16]. Until that day comes, however, Dr. Moussa's attempt to bring a low-cost IVF-ICSI program to the Beka'a Valley is an ethically sound act of reproductive justice. Although two standards of clinical care might result—with high-quality care in Beirut and lower-quality care in the Beka'a Valley—those patients who *are* helped by Dr. Moussa's low-cost IVF-ICSI program will be tremendously grateful, especially those to whom precious "test-tube" babies are born.

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## ETHICS CASE

### How Should Trainees Respond in Situations of Obstetric Violence?

Commentary by Nicholas Rubashkin, MD, MA, and Nicole Minckas, MSc

#### Abstract

Argentina passed a law for humanized birth in 2004 and another law against obstetric violence in 2009, both of which stipulate the rights of women to achieve respectful maternity care. Clinicians and women might still be unaware of these laws, however. In this article, we discuss the case of a fourth-year medical student who, while visiting Argentina from the United States for his obstetric rotation, witnesses an act of obstetric violence. We show that the student's situation can be understood as one of moral distress and argue that, in this specific instance, it would be appropriate for the student to intervene by providing supportive care to the patient. However, we suggest that medical schools have an obligation to better prepare students for rotations conducted abroad.

#### Case

Paul is a fourth-year medical student doing an away rotation in high-risk obstetrics in Buenos Aires, Argentina. He is part of the third-wave of medical students from a prestigious US medical school rotating at this hospital, which is where students from the local medical school also train. Paul's medical school helped to build this Buenos Aires-based medical school five years ago.

Before traveling to Argentina, Paul met with his friend, Bethany. "Watch out when you're on the labor floor," Bethany warned him. "You might see some violence toward the patients. I certainly did."

Upon learning this, Paul looked up issues about violence in labor and delivery settings and found that the term "obstetric violence" is used to describe a broader range of health care professionals' behaviors and communications that dehumanize, pathologize, and abuse women during "reproductive processes," especially childbirth. Paul learned that instances of obstetric violence are documented in numerous countries, including the United States, even though no US law expressly prohibits obstetric violence.

Now on the labor floor at the hospital in Buenos Aires, Paul observes resident physicians and nurses interacting with women delivering babies. In one case, Paul sees a resident physician yelling at a patient who has been pushing for over four hours. Loudly and

punitively, he tells her that she will most likely need an operative vaginal delivery or a cesarean section. He points his finger crudely at her vagina, threatening to do an episiotomy. He degrades her further, "You're so weak! I need you to push! Animals can push their babies out harder than that! Get going!" The patient's nurse hits her on the arm and points to her vagina, "You need to push harder, or the doctor is going to cut you."

Paul steps back, upset and trying to collect his thoughts. "This is so obviously wrong," he thinks. "What should I do?"

### **Commentary**

The mistreatment of parturient women in health care delivery settings is a form of violence that is embedded both in health systems and in the hierarchical power structures within hospitals [1]. In 2014, the World Health Organization published a statement to draw attention to the mistreatment of pregnant women in birth facilities [2]. In a commonly used framework in global health, Bowser and Hill detailed several categories of mistreatment including physical abuse, nonconsented care, nonconfidential care, nondignified care, discrimination, abandonment of care, and detention in facilities [3]. Somewhat distinct from this framework, several countries in Latin America have framed the mistreatment of parturient women from the perspective of dehumanizing experiences that result from the inappropriate medicalization of natural processes in childbirth [4]. Brazil pioneered the discussion on humanization of birth care in 1993, but it was not until the 2000s that the term "obstetric violence" started to be used in childbirth activism and legislation [5, 6]. Both the humanization of birth movement and laws against obstetric violence advocate for birth as a normal event in which women should be in charge and medical interventions only used when necessary [7].

In this case, Paul begins to wonder if he should intervene in the abuse he observes. However, becoming an advocate in the moment of witnessing violence or reporting a potentially illegal incident after the fact are two actions that need to be approached delicately so as not to put the woman or the medical student at risk. Because of the compromised position of the patient and the student, the hosting and home medical schools might have a greater duty to intervene in situations of obstetric violence.

### **The Humanized Birth Movement in Argentina**

As part of the region's efforts to demedicalize birth, in 2004 Argentina passed a law for humanized birth that put forward the rights of every pregnant woman to information as well as to dignified, respectful, and high-quality maternity care [8]. In 2009, following Venezuela's first institutional recognition of obstetric violence under the Organic Law on Women's Right to a Life Free of Violence [9], Argentina enacted a law against obstetric violence [10]. This law frames obstetric violence as a gender rights issue and defines it as a type of violence executed by health personnel on the woman's body and her

reproductive processes that is frequently expressed through dehumanized treatment, as was the case with the birth Paul witnessed.

It is important to stress that regulations under the 2004 Law for Humanized Birth in Argentina were not set out in detail until 2015 [11]. Due to this law's novel nature, hospitals, physicians, clinics, and even pregnant women might not be aware of their rights and responsibilities or of prohibited behaviors in the delivery suite [12]. After the passage of a law, behavior change can be slow and might require that citizens pursue accountability in a public fashion. Since the passage of the obstetric violence law, only one woman has initiated a legal proceeding against her physician [13].

The resident physician's verbal abuse and the nurse's physical abuse in this case are expressly forbidden under Argentine law. Types of verbal abuse during childbirth identified in literature reviews include harsh or rude language, judgmental or accusatory comments, and blaming for poor outcomes. Types of physical abuse identified in literature reviews include women being beaten, slapped, kicked, or physically restrained to the bed during delivery [14]. By these criteria, Kruk et al. found in postpartum interviews with 593 women in Tanzania that 13 percent experienced shouting or scolding, 11 percent reported threatening or negative comments, and 5 percent experienced slapping or pinching [15]. Bohren et al.'s interviews with Nigerian health care practitioners and women of reproductive age revealed that they believed abusive behaviors to be acceptable measures to get women to cooperate with the care plan or to optimize outcomes for the baby [16]. These findings indicate that [mistreatment during childbirth](#) is not restricted to Latin America but is also prevalent in other regions of the world.

### **Medical Students and Moral Distress**

Before discussing Paul's options to intervene or not in this situation, it is important first to frame his reaction to what he witnessed in the delivery room. Paul is experiencing moral distress, defined by Berger as "the cognitive-emotional dissonance that arises when one feels compelled to act against one's moral requirements" [17]. Due to the poor behavior modeled by the resident and the nurse, Paul feels unsure about whether to speak up about what is "so obviously wrong."

The experience of moral distress is common in medical training. In a cross-sectional survey of health professions students in the United Kingdom (UK), 69.9 percent of female and 59.9 percent of male medical students reported witnessing a senior clinician breaching patient dignity or safety, and 80.4 percent of female and 71.5 percent of male medical students reported being victims of abuse themselves [18]. Across all professionalism dilemmas, women reported being significantly more likely than men to classify themselves as distressed [18]. We don't know how common moral distress is for students in the cross-cultural context; focus groups conducted with faculty experts in

global health revealed that students confront ethical dilemmas concerning respect for patient autonomy and power dynamics [19].

### **On What Grounds Might Action Be Justified?**

Paul has two routes of action: intervening in the moment of the abuse or reporting the incident to the proper authorities in a reasonable amount of time. Intervening in the moment could be grounded in the bioethical principle of justice that compels professionals to protect the rights of the patient. The Argentine law for humanized birth clearly states that verbal and physical abuse of pregnant women is a violation of their rights [6]. Given that abuse in childbirth can impact a woman's physical and psychological health including greater risk of postpartum depression or posttraumatic stress disorder (PTSD) [20], Paul could also justify intervening based on the principle of nonmaleficence. Thus, solid ethical principles support an immediate action.

On the other hand, Paul must balance potential actions against other considerations arising from his position as a medical student in an Argentine hospital where he might have incomplete information about the unit culture and hospital routines. If Paul's intervention involves [challenging the resident's management](#) of an "abusive" situation, the resident could be put on the defensive, potentially worsening an already antagonistic situation. Although the resident might have committed an illegal act, he is likely providing adequate clinical care to this patient; an antagonistic situation could compromise clinical care. Finally, becoming an advocate in the moment might open up the possibility of Paul himself being harassed and abused. Given these possibilities, notifying the resident of his abusive behavior would be difficult to justify on the grounds of beneficence or nonmaleficence.

Paul might also need to consider whether he is legally obligated to act. According to Argentina's law against obstetric violence, anyone who witnesses an incident of obstetric violence should report it to the competent administrative authority determined by the local jurisdiction [10]. In reality these mechanisms would be difficult for a foreign medical student to navigate. However, it would be relatively safe for Paul to give the patient information about her rights under the law for humanized birth. From this point forward, the patient could decide whether it was in her best interests to pursue legal recourse.

### **Potential Solutions**

*Supportive care for laboring and postpartum women.* Fortunately, for a medical student like Paul who feels compelled to act in response to moral distress, there is a relatively simple way to intervene—namely, Paul could propose providing supportive care to the laboring woman. Supportive care would include emotional and physical support, listening to the pregnant woman's concerns, or helping her feel empowered. Evidence shows that women who are supported during labor—by a male partner, a health care worker, or a

doula (a trained assistant for birth and postpartum support)—report lower levels of mistreatment [21]. Continuous support also has clinical benefits. In a systematic review encompassing 15,061 women in 21 clinical trials, women who had continuous labor support were more likely to have a spontaneous vaginal birth, less likely to use epidural anesthesia, and less likely to report dissatisfaction [22]. With the patient's permission, Paul could accompany the woman through the rest of her labor, or, if the patient expressed concerns about involving Paul directly, he could facilitate involvement of her family. Finally, in contrast to the above possibility of confronting the resident and the nurse about their abusive behaviors, the medical team would be more likely to view Paul's supportive care in a favorable light.

Having established a relationship with the patient during her labor, Paul could continue supportive care into the postpartum period. Postpartum hospitalizations in Argentina normally last 2-4 days [23], and in our experience it is common for medical students to round on the patients whose births they observed. For women who have experienced potentially abusive situations, our approach is to create space for the woman to name her own experience; we believe it would be inappropriate for a medical student to name the abusive experience for her. Paul could create space for the patient by asking open-ended and nonjudgmental questions to probe the woman's perspective on her labor experience and help her arrive at her own conclusions. If the woman is already identifying her birth experience as abusive, then the medical student could inform her about the law for humanized birth and the law on obstetric violence. Either way, Paul should connect the patient to the hospital's psychosocial support services, since women who experience abuse in childbirth are at risk for poor postpartum mental health outcomes [24].

*Institutional responses to obstetric violence.* Most medical students will likely experience moral distress whether at home or abroad. While some experts have suggested that [emotional support interventions](#) might be helpful to students [18], others have argued that an institutional response would be more effective [17]. However, we have no information on effective institutional responses to moral distress in the global context.

Nonetheless, we believe that the sending and receiving institutions have a duty to prepare students for the contexts into which they will be inserted. Jogerst et al. have helpfully detailed the proposed knowledge, attitudes, and skills required for learners in global health, which can serve as a guide for clerkship directors [25]. It does not appear that Paul was appropriately supported to achieve competency appropriate to his level. Instead, Paul learned about the potential for abusive situations in childbirth from a returning medical student, quite apart from the official curriculum. To better prepare students, clerkship directors from home and host institutions could incorporate general material on global health competencies and moral distress and specific material on respectful maternity care.

For instance, the Argentine and American obstetric clerkship directors could create the space for medical students to do formal presentations on the global and national evidence concerning the mistreatment of pregnant women, including the different types of mistreatment, their prevalence, and their impact on women's and newborn's health. Clerkship directors need to prepare students in appropriate ways to intervene if abusive situations arise in childbirth, especially in how to provide supportive care and how to work collaboratively with the clinical team. Finally, in Paul's case, given the specific nature of the reporting mechanisms, the Argentine clerkship director should make it clear to whom students should report potentially abusive behaviors.

It can be difficult to challenge strongly held beliefs about and ingrained patterns of practice in childbirth. As trainees, medical students play an important role in learning to become respectful maternity care clinicians. A systematic review performed by Mannava et al. found widespread negative attitudes held by maternity care physicians toward pregnant women in low- and middle-income countries, suggesting that long-term investments in health system infrastructure and in health care workers' education, communication skills, and work-life balance will be key to training the next generation [26].

### **Conclusion**

With regulations in place, achieving a national-level commitment to respectful maternity care in Argentina is possible. With the right institutional structure, rotating medical students can play an important role in advancing respectful maternity care abroad. If an institutional structure is lacking, students can provide supportive care to laboring women—a well-established intervention to improve the birth experience and prevent mistreatment. Students can also inform women of their legal rights; however, it would be challenging for an American student to report obstetric violence under Argentine law. When guidelines are lacking, students should push for clear expectations from their clerkship directors about whether and to whom they should report incidents of obstetric violence.

Efforts to improve maternity care go beyond the legal recognition of obstetric violence and the health care professional's in-the-moment reaction to an instance of mistreatment of a pregnant woman. The cooperating medical schools should assume responsibility to inform students about different norms and behaviors and prepare them to react adequately in situations that create moral distress. If Paul's friend had not informed him about this type of mistreatment of pregnant women, he would have arrived in Argentina unaware of the legal framework or without a previous consideration of his ethical role.

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## THE CODE SAYS

### The AMA *Code of Medical Ethics*' Opinions Related to Global Reproductive Health

Scott Schweikart, JD, MBE

#### Abstract

The American Medical Association (AMA) *Code of Medical Ethics* offers guidance on reproductive health. Assisted reproductive technology raises ethical issues of respect for patient autonomy, privacy, informed consent, and discrimination, and it has societal consequences with ethical implications. The *Code* also addresses economic inequalities, access to health care, and disparities in health care broadly enough to be relevant to global reproductive health.

#### Introduction

Global reproductive health is a broad issue that raises ethical concerns related to reproductive technology (all reproductive treatments or procedures that handle human oocytes or embryos), economic inequalities, health care access, and gender and racial disparities. The *Code of Medical Ethics* offers guidance on many of these issues.

#### Reproductive Technology

The *Code* addresses issues of reproductive medicine most directly in Chapter 4.2, which gives guidance on several key issues related to reproductive medicine that have arisen because of modern technology. Some of the important ethical issues raised are respect for patient autonomy, privacy, informed consent, discrimination, and broader societal consequences.

*Respect for patient autonomy.* Opinion 4.2.1, "Assisted Reproductive Technology" [1], explains that "candor and respect are ... essential for ethical practice," as patients who have difficulty in having children are often "psychologically very vulnerable." With the aim of fostering increased respect for patient autonomy, Opinion 4.2.1 also states that "physicians should increase their awareness of infertility treatments and options for their patients. Physicians who offer assisted reproductive services should ... value the well-being of the patient and potential offspring as paramount" [1]. Similarly, with regard to sperm or egg donors, Opinion 4.2.2, "Gamete Donation" [2], states that physicians should "discuss, document and respect the prospective donor's preferences for how gametes may be used, including whether they may be donated for research purposes."

*Privacy.* Opinion 4.2.2 recognizes the “concerns about the privacy of donors and the nature of relationships among donors and children born ... through use of their gametes by means of assisted reproductive technologies.” Physicians should therefore “inform prospective donors ... under what circumstances and with whom personal information, including identifying information, will be shared for clinical purposes” [2]. Physicians should also “discuss, document, and respect the prospective donor’s preferences regarding [release of identifying information](#) to any child (or children) resulting from use of the donated gametes” [2].

*Informed consent.* Opinion 4.2.3, “Therapeutic Donor Insemination,” states that “physicians who choose to provide artificial insemination should ... obtain informed consent for therapeutic donor insemination, after informing the patient (and partner, if appropriate)” [3]. Opinion 4.2.2 explains that physicians should “inform prospective donors ... about the clinical risks of gamete donation ... including the near and long-term risks and the discomforts of ovarian hyperstimulation and egg retrieval as appropriate” and “about the need for full medical disclosure and that prospective donors will be tested for infectious disease agents and genetic disorders” [2]. Opinion 4.2.2 additionally states that physicians should inform donors “whether and how the donor will be informed if testing indicates the presence of infectious disease or genetic disorder,” “under what circumstances ... personal information ... will be shared,” “how donated gametes will be stored,” and “whether and how the donor will be compensated” [2]. Similarly, Opinion 4.2.4, “Third-Party Reproduction,” states that physicians should “inform the patient about the risks of third-party reproduction for that individual,” including “possible psychological harms to the individual(s), the resulting child, and other relationships” and that physicians should “satisfy themselves that the patient’s decision to participate in third-party reproduction is free of coercion” [4].

In addition to informing donors and patients about medical risks, the *Code* provides guidance on storage of embryos created for IVF treatment that are not intended for immediate transfer. Opinion 4.2.5, “Storage and Use of Human Embryos,” explains that physicians have

an ethical responsibility to proactively discuss with the parties whether, when, and under what circumstances stored embryos may be ... used by a surviving party for purposes of reproduction in the event of the death of a partner or gamete donor ... made available to other patients for purposes of reproduction ... made available to investigators for research purposes ... [and] allowed to thaw and deteriorate ... [or] otherwise disposed of [5].

*Discrimination.* Opinion 4.2.1 states that physicians who offer assisted reproductive services should not “discriminate against patients who have difficult-to-treat conditions,

whose infertility has multiple causes, or on the basis of race, socioeconomic status, or sexual orientation or gender identity” [1]. For example, regarding artificial insemination (using sperm from a third-party donor to help a woman achieve pregnancy), Opinion 4.2.3 states that “physicians who choose to provide artificial insemination should ... provide therapeutic donor insemination in a nondiscriminatory manner. Physicians should not withhold or refuse services on the basis of nonclinical considerations, such as a patient’s marital status” [3].

*Societal consequences.* Opinion 4.2.4 states that “collectively, the profession should advocate for public policy that will help ensure that the practice of third-party reproduction does not exploit disadvantaged women or commodify human gametes or children” [4]. The *Code* also addresses the potential harms of reproductive cloning (use of somatic cell nuclear transfer to create a human embryo that shares all genes with the donor cell). Opinion 4.2.6, “Cloning for Reproduction” [6], explains that “reproductive cloning might be ethically acceptable to assist individuals or couples to reproduce and to create a compatible tissue donor” but that “reproductive cloning also carries the risk of psychosocial harm” to the cloned child. Opinion 4.2.6 further explains that cloning “may have adverse effects on familial and societal relations and on the gene pool.... Moreover, reproductive cloning has the potential to be used in a eugenic or discriminatory fashion—practices that are incompatible with the ethical norms of medicine” [6]. As such, “reproductive cloning is not endorsed by the medical profession or by society” [6].

### **Economic Inequalities and Access to Health Care**

Many women around the world face access problems when seeking quality care related to reproductive health [7, 8]. The *Code* discusses access to health care broadly enough to be relevant to reproductive health, which includes issues of scarcity, cost, and necessity [9–11]. Chapter 11.1 recognizes that disparate access to health care is a primary ethical concern to which physicians have an ethical obligation to respond. Opinion 11.1.1, “Defining Basic Health Care” [12], states that “society has an obligation to make access to an adequate level of care available to all its members.” Opinion 11.1.3, “Allocating Limited Health Care Resources” [13], states that physicians “should advocate for policies and procedures that allocate scarce health care resources fairly among patients.” Similarly, Opinion 11.1.4, “Financial Barriers to Health Care Access” [14], explains that “physicians individually and collectively have an ethical responsibility to ensure that all persons have access to needed care regardless of their economic means” and that physicians should “take steps to [promote access to care](#) for individual patients, such as providing pro bono care.”

### **Disparities in Health Care**

Health care disparities are a common theme of concern in public health. Indeed, as Julie Hwang notes:

Racial disparity in the healthcare system has been criticized as one of the major social and economic problems in the United States. Racial and ethnic minorities consistently face challenges in the healthcare system and subsequently face higher mortality, lower health status, and higher propensity for certain illnesses and diseases [15].

Opinion 8.5, “Disparities in Health Care” [16], explains that disparity “represents a significant challenge for physicians, who ethically are called on to provide the same quality of care to all patients.” Opinion 8.5 describes health care disparities as “differences in treatment that are not directly related to differences in individual patients’ clinical needs or preferences” and states that such differences “constitute inappropriate variations in health care” that “may contribute to health outcomes that are considerably worse” for members of certain [minority groups](#). To ensure quality of care, physicians should “avoid stereotyping patients” and “work to eliminate biased behavior toward patients” [16]. Opinion 8.5 further states that the medical profession has an ethical responsibility to “increase awareness of health care disparities” and “support research that examines health care disparities” [16].

### **Conclusion**

*The Code* offers guidance on issues related to global reproductive health, including ethical issues of patient autonomy, privacy, informed consent, discrimination, and societal consequences related to the use of reproductive technologies. The *Code* also offers guidance on issues of economic inequality, access, and disparities in health care, which are key factors related to global reproductive health.

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## MEDICAL EDUCATION

### Linking Global Health to Local Health within an Ob/Gyn Residency Program

Sara Whetstone, MD, MHS, and Meg Autry, MD

#### Abstract

An unprecedented number of medical students and residents express the desire to participate in global health work during their training and beyond. Preparing learners for work in underserved settings makes it more likely that they will continue to work in areas of need. Training programs that focus on global health have been criticized as there is ample work to be done in the US, and often global health work becomes learner-centric, which is difficult to maintain and potentially burdensome and harmful to the host site. In this article, we discuss a curriculum and training program that intentionally prepares learners to work responsibly and collaboratively in low-resource settings, both nationally and globally.

#### Introduction

Trainees are desirous of opportunities to work in global health settings during residency and afterwards. A recent survey revealed that many residents in obstetrics and gynecology even use their free time and own funds to secure such experiences [1]. Providing opportunities during training for work in international settings and in underserved domestic communities has the potential to increase the physician workforce ready to care for underserved populations. Residents and students who have experiences with underserved populations develop a more informed perspective on health care delivery, resource allocation, and cost effectiveness [2-5]. More importantly, students and residents who train in low-resource settings are more likely to work in underserved areas locally and abroad in the long term [2-5]. Yet one survey of US physicians showed that roughly three-fourths of respondents felt unable to address social determinants of health and ill equipped to provide quality care to underserved populations [6].

Since the evidence demonstrates that experiences in caring for underserved populations leads to extended commitments to work in areas of need, we believe that training programs should prepare residents to care for underserved populations in this country and globally. However, we reject the assumption that just working in an underserved community will lead to appropriate skill acquisition and expertise. While many programs have residents rotate through safety net hospitals and spend [elective time in international settings](#), at the University of California, San Francisco (UCSF), we believe

that we have further developed these experiences into a curriculum that improves health care provision for women by intentionally training residents to address the particular medical and nonmedical needs of underserved populations.

The mission statement of the obstetrics and gynecology residency program at UCSF is to improve the health and well-being of all women. We emphasize the word “all” as we embrace and value the notion of inclusivity. We assert that all women, domestically and internationally, with resources and without, deserve to have opportunities to improve their lives and make decisions about their bodies that are consistent with their values and goals. Given these values and assertions, our mandatory resident training includes deliberately structured, supported, and integrated educational experiences in both global and local health. In this paper, we describe our approach to training obstetrics and gynecology residents to care for vulnerable women in our community and in international settings.

### **Instituting Domestic Training Programs for Underserved Populations**

Many states in the US, including California, Texas, Georgia, and Wisconsin, have instituted programs in conjunction with their public academic institutions to help meet their workforce needs as well as address inequities in the provision of health care to their citizens [7-10]. In California, funding has been available since 1973 to support primary care programs to prepare physicians to work in under-resourced settings in the state [11]. In 2014, this opportunity was extended to obstetrics and gynecology programs [7], and the UCSF residency program was a fortunate recipient of this funding. Despite UCSF’s long history of commitment and service to underserved populations, this funding enabled us to implement a more robust and intentional curriculum on caring for vulnerable populations in our state and in our country. Our mandatory and integrated curriculum is entitled EMPOWUR—**E**ducating, **M**entoring, and **P**reparing **Ob/Gyns** to Care for **W**omen in **U**nder-**R**esourced communities. It aims to graduate obstetrician-gynecologists who are prepared, committed, and inspired to provide excellent care to underserved women within the United States. To accomplish this goal, we focus on the following four curricular pillars of the EMPOWUR program:

1. *A didactic curriculum.* The curriculum highlights issues of health and health care disparities, provides training in social determinants of health, and raises awareness about care for specific marginalized populations. These didactic activities have taken the form of grand rounds, traditional resident lectures, journal clubs, and supplemental evening didactic opportunities. Examples of topics include substance abuse in pregnancy, homelessness, and care for incarcerated women. The inclusion of such topics in our core curriculum reflects our belief that these learning areas are essential components of comprehensive [training in obstetrics and gynecology](#).
2. *Direct care in underserved communities.* Our second-year residents participate in a community-based clinical experience that differs from their

usual clinical work in hospital-based settings. During this required rotation, residents work directly in the community in clinics with extensive commitments to the surrounding neighborhoods and with limited resources and access to specialty care.

3. *Role modeling.* In these community-based settings, residents work with clinicians who have demonstrated long-term dedication to providing care to vulnerable populations. These [partnerships](#) expose trainees to career paths that they do not traditionally encounter within a tertiary care academic center; moreover, residents observe clinicians providing compassionate, evidence-based care and using innovative approaches despite constrained resources. Additionally, the program hosts an inspired speaker series featuring national leaders who have developed unique models of care for vulnerable populations. Past speakers have included Melissa Gilliam, who shared her innovative approach to engaging adolescents on Chicago's South Side in their care; and Willie Parker, who discussed his work on abortion care in areas of the South with restricted access. These speakers not only share their work in the larger forum of grand rounds but also spend time with our residents, discussing their motivations, career trajectories, and long-term goals.

4. *Activism and advocacy.* Recognizing that caring for vulnerable populations requires advocating for social change, health equity, and increasing access to health care along with other social services, our residents participate in departmental, interdisciplinary, community, and national trainings related to public advocacy for women's health. These trainings often spur individual and group action related to quality improvement projects in our own health system along with broader efforts concerning social justice and health. Our residents have lobbied against shackling of pregnant women, which became law in California in 2012 [12], and lobbied against repeal of the Affordable Care Act; currently, they are working to revise policies on drug testing in the labor and delivery suite to minimize racial disparities in testing and in reporting to child protective services.

The EMPOWUR curriculum not only strives to prepare residents to be clinically competent in the care of underserved women domestically but also hopes to equip trainees with the knowledge and skills necessary to recognize disparities, to develop trusting and [engaged relationships with the community](#), and to address nonmedical factors associated with health inequity. This long-term and broader vision for our training reflects the call for clinician-educators to prepare physicians to address social and institutional barriers to health [13]. While the EMPOWUR clinical experience is focused on vulnerable domestic populations and community work, the didactic curriculum and advocacy work is applicable internationally and complements our global health training.

## Creating Ethical Global Health Experiences for Trainees

In our didactic program, we have embraced a broader definition of global health—one that explicitly includes inequities both in our country and globally [14]. From a practical perspective, there has been increasing recognition that the skills needed to practice successfully in international settings—such as those required to surgically manage postpartum hemorrhage and provide safe, respectful maternity care—are similar to those needed to work with underserved populations in our own country [15]. By timing the global health experience to chronologically follow the clinical experience of the EMPOWUR program, residents are better prepared in terms of their skills and knowledge and, more importantly, better positioned to engage with local physicians in their efforts to address disparate outcomes.

Our curriculum in global health occurs primarily in the third year of residency and includes an online didactic course as well as an experiential component. UCSF obstetrics and gynecology residents spend four weeks at Mulago Hospital, the teaching hospital affiliated with Makerere University College of Health Sciences in Kampala, Uganda; they rotate alongside Ugandan house staff and provide advanced obstetric and gynecologic care. Mindful of the pitfalls of short-term experiences in global health, our program has been deliberately structured to maximize benefits to the host community while at the same time augmenting the learner's experience in understanding global inequity [16].

Key features of our global health program include:

1. *A long-term commitment to a particular country and institution.* This commitment allows relationship building, collaborative research, skills transfer, and longitudinal work on quality improvement initiated and led by the host partners. UCSF has partnered with Makerere University since 1998 primarily in the area of HIV and malaria research. For the last ten years, there has been a strong collaboration between the departments of obstetrics and gynecology at Makerere University and UCSF.
2. *A requirement of learner preparation prior to departure.* This requirement compels trainees to engage in active learning prior to beginning clinical work in Uganda. Trainees are introduced to diseases like malaria and tuberculosis that are not commonly encountered in the US as well as health conditions like ectopic pregnancy and preeclampsia that are seen in both environments but treated differently in Uganda due to limited resources. Mandating that trainees prepare before they travel allows them additional time and space during their rotation in Uganda to concentrate on larger issues related to delivery of care, innovations in care, and health inequities. The predeparture curriculum also includes topics focusing on safety and different cultural beliefs.
3. *Traveling with a faculty member experienced in global health.* This arrangement offers support for residents. Trainees spend approximately four weeks abroad and often speak about the incredible disparities in care and

health status that they see; providing residents with a familiar and safe faculty mentor allows them to reflect on and process the clinical care they witness and in which they participate.

4. *Investment in capacity building at Makerere University.* Although faculty members travel with residents, their primary goal is to participate in skill-building opportunities for clinicians in Uganda and to provide research mentorship and collaboration for topics generated by the Ugandans. Additionally, faculty members have fostered a bidirectional relationship in which several of the Ugandan physicians travel to the United States to advance their professional skills by engaging in research efforts, delivering grand rounds, presenting at scientific meetings, and obtaining additional clinical training.

We have developed a supportive and collaborative global health experience that strives to link global health and local health training and facilitate greater conversation about equity, social justice, and interconnectedness. Our pedagogical approach to global health education is one in which trainees are taught how to provide responsible, equitable care and challenged to transfer these principles and clinical approaches to the clinical setting in which they work. Additionally, faculty members strive to model collaborative and bidirectional work with local agencies and Ugandan physicians, hoping to demonstrate principles of community engagement that can be used in communities abroad and in our own backyard. We believe that global health training, when properly structured, adds to trainees' preparation in caring for marginalized women and increases the likelihood that they will ultimately work to address disparity in their careers.

### **Conclusion**

We believe that we have constructed a robust curriculum on caring for underserved populations that emphasizes didactic and experiential exposure both locally and globally. In order to improve the health of all women, we feel an obligation to adopt a more expansive approach to clinician education that includes intentional preparation for work in low-resource settings. Accordingly, we aim to train clinically competent women's health practitioners who have the skills needed to care for marginalized populations and to address social and institutional barriers to health. While this paper has focused on women's health and training in obstetrics and gynecology, the concepts and principles are certainly applicable to most specialties. By pairing curriculum and experiential learning in both domestic and global health, we hope to encourage future work with underserved populations in our state, our nation, and our world. We believe that residents who participate in our unique curriculum are more likely to pursue this path and be content in their choice because they are exposed to the benefits and realities of this work. We hope that our educational model inspires our trainees to develop a larger vision of patient care, one in which they can continue to address inequities and to improve women's health, regardless of where they choose to practice.

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## STATE OF THE ART AND SCIENCE

### Balancing Demand for Universally Improved Health Outcomes with Need for a Local Standard of Care

Christina Krudy, MD, and Kavita Shah Arora, MD, MBE

#### Abstract

The United States, along with other resource-rich countries, leads global health care by advancing medical care through randomized controlled trials (RCTs). While most medical research is conducted in these resource-rich areas, RCTs, including replications of previous trials, are additionally carried out in low- and middle-income countries. On the basis of positive findings from several RCTs conducted in high-income countries, the Antenatal Corticosteroids Trial (ACT) evaluated the effectiveness of antenatal corticosteroids in reducing neonatal mortality in low- and middle-income countries. ACT, however, was undertaken in dramatically different health care infrastructures and did not confirm the results of previous studies. We argue that it is neither clinically appropriate nor ethically acceptable to extrapolate findings from one region to another without accounting for the disparate cultural values, goals of care, and health services infrastructure that impact clinical outcomes.

#### Introduction

As the gold standard of clinical research, randomized controlled trials (RCTs) produce generalizable results when properly conducted. However, in the quest to improve global health, it is easy to overlook issues of generalizability, which depends on the sample of participants being representative of the target population. Results of an RCT conducted in one country might not generalize to another due to differences in patient characteristics, social determinants of health, national economic status, health care infrastructure, health services, and legal context. While a well-done RCT ideally acknowledges and accounts for participant-level clinical and demographic differences, the social and health systems in which care is provided in the target population can mistakenly be assumed to be constant rather than variables in the health care equation [1, 2].

These difficulties are highlighted by the discrepant results of two RCTs on antenatal glucocorticoid administration to prevent neonatal respiratory morbidity—the Antenatal Corticosteroids Trial (ACT) and the Antenatal Late Preterm Steroids (ALPS) trial [1, 2]—

conducted in different regions. The lessons learned from these trials present bioethical considerations that need to be taken into account when endeavoring to improve health outcomes globally. After analyzing both overlooked clinical assumptions and ethical issues, we argue that it is neither clinically appropriate nor ethically acceptable to extrapolate findings from one region to another without accounting for the disparate cultural values, goals of care, and health services infrastructure that impact clinical outcomes. In our diverse and global health care system, it is important to remember that, ultimately, all care is local.

### **Clinical Context**

Antenatal corticosteroids (ACS) as a means of reducing adverse neonatal outcomes in at-risk preterm births first came to light in 1972 [3]. These steroids are given to pregnant mothers at risk for preterm delivery to improve neonatal respiratory function. In the United States, evidence strongly supports the use of ACS to help reduce [respiratory distress syndrome](#) and death in preterm infants less than 34 weeks of gestational age, and the decrease in neonatal morbidity and mortality nationally following preterm birth is thought to be strongly related to glucocorticoid administration [1, 4-6].

The majority of trials evaluating the effectiveness of ACS limited use to a gestational age of less than 34 weeks until the publication of the ALPS trial in 2016. The ALPS trial was a large, multicenter, RCT conducted in the United States that sought to determine whether ACS had a role in improving neonatal outcomes when given in the late preterm period from 34 weeks 0 days to 36 weeks 5 days [1]. The ALPS trial demonstrated a positive impact from administering late preterm ACS, including reduced rates of resuscitation at birth, surfactant use, transient tachypnea of the newborn, and bronchopulmonary dysplasia [1]. The study did not detect a significant difference in rates of maternal infection (chorioamnionitis or endometritis) between groups, and there were no neonatal deaths in either study arm. As a result of the ALPS trial's findings, the American College of Obstetricians and Gynecologists expanded its recommendations on ACS therapy for fetal maturation to include consideration of routine administration to pregnant women between 34 weeks 0 days and 36 weeks 6 days who were at risk of preterm birth within 7 days and who had not received a previous course of ACS [5].

Given the success of ACS in the United States and other high-income countries such as Finland, Brazil, Spain, United Kingdom, New Zealand, and the Netherlands, among others, the World Health Organization (WHO) has recommended the use of ACS for women at risk for preterm delivery to help improve preterm birth outcomes [7, 8]. The National Institutes of Health published a conference report addressing the expanded use of ACS in low-income countries to help reduce high rates of neonatal death and morbidity attributed to prematurity [9]. In general, antenatal corticosteroids are recommended for use in low-income countries, ideally at a hospital with high-level care

[9]. But these recommendations warrant caution as they also acknowledge a lack of data regarding the efficacy of ACS in these countries.

In response to this need, the WHO recently announced plans for two upcoming trials to further evaluate the efficacy of ACS use in low-income countries [10, 11]. The two trials will look at ACS use in gestational ages 26 weeks 0 days to 33 weeks 6 days and 34 weeks 0 days to 36 weeks 0 days, respectively. The RCTs will be held in Bangladesh, India, Kenya, Nigeria, and Pakistan at hospitals with sufficient levels of maternal and newborn care [10, 11]. These trials, also known as the WHO Antenatal Corticosteroids for Improving Outcomes in Preterm Newborns (WHO ACTION) trials, will seek to answer questions raised by the results of the ACT trial given the limitations of generalizability to the diverse populations that exist in low- and middle-income countries [10, 11].

Prior to the announcement of the WHO ACTION trials, the first randomized controlled trial analyzing ACS use in low-income countries was published in 2015. In an effort to expand ACS use and evaluate its feasibility and effectiveness in low- and middle-income countries, Althabe et al. launched a cluster-randomized trial in six countries with high rates of premature birth via the ACT trial [2]. Pregnant women before 36 weeks of gestational age at risk for preterm delivery were randomized to receive ACS in Argentina, Guatemala, India, Kenya, Pakistan, and Zambia. Health care practitioners were trained to identify women with signs of labor and medical conditions that could necessitate an indicated preterm delivery. They also received instruction on how to accurately estimate gestational age, as the availability of ultrasonography was limited. The primary outcome measured was 28-day neonatal mortality among infants less than the 5th percentile for birth weight to act as a proxy for preterm gestational age. Despite the increased use of ACS in the study treatment arm, however, the study found no difference in neonatal mortality between the treatment and control arms, an overall small increase in neonatal mortality in the study population as a whole, and an increased rate of maternal infection in the women who received ACS [2]. These findings came as a surprise given the publication of 30 trials demonstrating a positive benefit and showing a reduction in perinatal death, neonatal death, and respiratory distress syndrome [8]. These incongruent results raised questions regarding the generalizability of previous trials.

### **Addressing Overlooked Clinical Assumptions in Research**

The comparison of the ALPS trial to the ACT trial calls attention to several overlooked implicit clinical assumptions. The ACT trial investigators are thoughtful when addressing the challenge of determining gestational age by looking at birth weight less than the 5th percentile as a proxy for length of pregnancy. As the authors acknowledge, one weakness of the study is that term infants with intrauterine growth restriction were possibly included while missing preterm infants with higher birth weights, both of which could have contributed to lack of an observed positive effect since gestational age has a greater impact on lung development than weight. This is in stark contrast to the ALPS

study conducted only using participants with excellent dating of their pregnancies due to the availability of prenatal care and antenatal ultrasounds.

It is also crucial to consider several assumptions one might make about a disease and subsequent treatments in another global territory. Disease pathology might not be the same between regions. In fact, data suggest that the underlying etiology for preterm birth varies based on geographic location [12]. For example, higher rates of infections such as HIV, STDs, and malaria are thought to be partly related to the exceedingly high rates of preterm birth in Africa [13]. If rates of infection as a cause of preterm birth are higher in low-income regions, it would be reasonable to predict that ACS use in this population could lead to a higher incidence of maternal sepsis as steroids also act as an immune suppressant [14]. In fact, in a systematic review of 21 RCTs evaluating the effects of ACS use, 8 did show a trend, though not statistically significant, of increased puerperal sepsis [8]. Therefore, along with studying the heterogeneity in results of ACS administration between high-income and low-income countries, researchers should also investigate the potentially varying basis for preterm birth in low-income countries.

Medical care should also not be taken as an isolated event in time. Proper follow up and long-term care must be a consideration for premature infants. For example, it is unclear the extent to which the lack of skilled attendants at birth and decreased availability of adequate postnatal care impacted the results of the ACT trial. The ACT trial's criteria for cluster centers was based upon birth registries with at least 300 births annually, whether these occurred at homes or facilities [2]. While the study interventions also included training in essential newborn care, there is no mention of quality assurance among health care practitioners. The majority of women did deliver in health care centers but there were still reported [home births](#) [2]. Additionally, there were differences between the treatment and control group regarding type of skilled attendant and delivery location [2]. Women in the treatment arm tended to deliver in a clinic with a nurse as the skilled attendant, whereas the control arm had more hospital deliveries with physicians. Taken together, the divergent outcomes between the ALPS and ACT trials might be explained by the variation in study methodology, especially the study populations, as well as the varying health care infrastructures in which care was provided.

### **Ethical Challenges in Extrapolating Research Findings Globally**

The disparate results of the ALPS and ACT trials demonstrate the importance of an adequate understanding of the cultural context as well as the risks of insufficiently accounting for the health services environment of different countries when attempting to extrapolate research findings. Physicians have an ethical responsibility to be mindful of potential hazards or challenges that exist in underdeveloped countries that might impede or undermine patient care when applying successful treatments that have only been studied in specific target populations.

In addition to assumptions made about a disease's epidemiology, it is imperative to be mindful of a region's values, goals of care, health care infrastructure, and resources when bringing treatments abroad or designing replications of previous research trials. While the ACT trial was successful at increasing rates of ACS administration in six low- and middle-income countries [2], increasing neonatal and maternal care overall poses a more difficult challenge, since a substantial proportion of women deliver in their homes [12]. It might not be culturally desirable, or logistically feasible, for these women to deliver in a hospital [15]. Economic status and local resources also deserve attention when considering the application of biomedical research findings. For example, the cost-benefit ratio of a variety of interventions for improving maternal and infant health can differ within low-income regions. Using the number of disability-adjusted life years averted, a metric that combines both mortality and morbidity in order to determine the cost of disease burden, one report found ACS to be the *least* cost-effective intervention among others such as breastfeeding support, tetanus toxoid vaccines, and treatment of syphilis in South East Asia [16]. Thus, resources might better be allocated in these countries to interventions known to have greater impact on population health than ACS.

Designing an ethical research study, especially in the era of global health, requires thoughtful balance. The study should be conducted in populations that are sufficiently narrowly demarcated to account for the relevant variations in culture and in health systems that might impact the results. An appropriate response to this dilemma is demonstrated in the new WHO ACTION trials, as previously discussed [17]. However, the study population should also be sufficiently broadly defined to potentially include as many patients as possible and not exclude groups of people from having the opportunity to serve as research participants. Finally, the group of people serving as research participants must have the opportunity to directly or indirectly benefit from the results.

### **Conclusion**

The medical community is thus left with the challenge of how to reconcile different results from research trials conducted in a global health care system comprised of varying cultural contexts and health care infrastructures. The global health care community must push itself to be thoughtful and critical when seeking to apply results from RCTs conducted in resource-rich regions to an entire international community. Furthermore, it is imperative to realize that while the desire to improve health outcomes must be global, such efforts should be cognizant of local values, culture, resources, and health care infrastructure. While the actual medical care and thus standard of care recommendations might vary between regions given these differences, conducting research globally remains of high importance.

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## POLICY FORUM

### Why Crisis Pregnancy Centers Are Legal but Unethical

Amy G. Bryant, MD, MSCR, and Jonas J. Swartz, MD, MPH

#### Abstract

Crisis pregnancy centers are organizations that seek to intercept women with unintended pregnancies who might be considering abortion. Their mission is to prevent abortions by persuading women that adoption or parenting is a better option. They strive to give the impression that they are clinical centers, offering legitimate medical services and advice, yet they are exempt from regulatory, licensure, and credentialing oversight that apply to health care facilities. Because the religious ideology of these centers' owners and employees takes priority over the health and well-being of the women seeking care at these centers, women do not receive comprehensive, accurate, evidence-based clinical information about all available options. Although crisis pregnancy centers enjoy First Amendment rights protections, their propagation of misinformation should be regarded as an ethical violation that undermines women's health.

#### What Are Crisis Pregnancy Centers?

Drive down any highway in America, and you might see a sign: "Pregnant? Scared? Call 1-800-555-5555." Most often, these signs are advertisements for crisis pregnancy centers (CPCs). CPCs, sometimes known as "pregnancy resource centers," "pregnancy care centers," "pregnancy support centers," or simply "pregnancy centers," are organizations that seek to intercept women with unintended or "crisis" pregnancies who might be considering abortion. Their mission is typically to prevent abortions by persuading women that adoption or parenting is a better option [1, 2]. One of the first CPCs opened in 1967 in Hawaii [3].

Most CPCs are religiously affiliated [4], and a majority are affiliated with a network or umbrella organization such as Birthright International, Care Net, Heartbeat International, or the National Institute of Family and Life Advocates [1, 3]. These umbrella organizations offer legal support, ultrasound training, and other services to CPCs. With an estimated 1,969 network-affiliated CPCs in the US in 2010 [1], CPCs outnumber abortion clinics, which were estimated at 327 as of 2011 [5]. Many state governments fund CPCs through mechanisms such as "Choose Life" specialty license plates and grants, and many also receive federal funding [3, 6].

In this article, we will argue that both the lack of patient-centered care and deceptive practices make CPCs unethical. We will first highlight the discrepancy between the lack of standards for quality of care provided by CPCs and the innumerable restrictions on abortion clinics. We then show that CPCs violate principles of medical ethics, despite purporting to dispense medical advice. Finally, we will review legal challenges to CPCs, including an upcoming Supreme Court case, and regulatory challenges in an industry that seeks to be perceived as providing health care while simultaneously seeking to elude the need to be held to evidence-based standards of caring for women with unexpected pregnancies.

### **What Do Crisis Pregnancy Centers Do?**

What might not be immediately apparent to someone seeking help at a CPC is that these centers take a distinct anti-abortion approach to pregnancy in that unintended or “crisis” pregnancies have two viable options, adoption or parenting. Multiple “undercover” or “secret shopper” surveys of CPCs and detailed reviews of the centers’ promotional materials and websites reveal that these centers give the impression of being medical clinics or having medical expertise [3, 7-9]. Often using neutral-sounding language, these centers offer to help women with free pregnancy tests, [ultrasounds](#), testing for sexually transmitted infections, and counseling on “all options” for pregnancy. In addition, pregnant women are often offered resources such as maternity clothes, diapers, and parenting classes. These centers often offer to give a “pregnancy verification” form, which women can use to enroll in prenatal care or to apply for government assistance with medical care (e.g., Medicaid or the Special Supplemental Nutrition Program for Women, Infants, and Children) [3, 8, 9].

CPCs, as a rule, not only discourage abortion but also refuse to provide referrals to abortion clinics, although they often provide “counseling” about “dangers associated with premarital sexual activity” [10]. Women who visit CPCs typically do not realize that they are not in an abortion clinic and are surprised to find that abortion is not considered an option at these centers [3]. As obstetrician-gynecologists, we have had several disgruntled patients come to us who were disappointed and felt deceived by the care that they had received at CPCs.

### **Arguments against Crisis Pregnancy Centers**

CPCs have received criticism from lawmakers, physicians, scholars, and reproductive rights organizations for many of their practices [2, 3, 11]. They strive to appear as sites offering clinical services and unbiased advice. Lay volunteers who are not licensed clinicians at CPCs often wear white coats and see women in exam rooms [3, 8]. They also purport to provide medical advice on a variety of issues, including sexually transmitted infections, early pregnancy, and abortion [3, 8]. Because centers are sometimes located close to abortion clinics and have names and logos similar to nearby abortion clinics,

women could mistakenly seek care there rather than at the intended clinic. They also seek to target women who are most likely to seek abortion, particularly low-income women and women of color [12]. These strategic practices appear designed to mislead abortion clinic clients [3, 8].

Despite looking like legitimate clinics, most CPCs are not licensed [9, 13], and their staff are not licensed medical professionals [13]. CPCs that are not licensed medical clinics cannot legally be held to the privacy provisions of the Health Insurance Portability and Accountability Act (HIPAA) [3], which could lead to violations of [client privacy](#). For example, client information might not be kept confidential, and information about pregnancy or abortion intentions might be shared with people outside the clinic [14, 15]. Some CPCs have adopted a “Commitment of Care and Competence” statement that is provided by umbrella organizations, such as Heartbeat International and Care Net [16, 17]. This statement includes provisions on patient confidentiality and accurate clinical information; however, adoption of these guidelines is optional and adherence is not regulated or enforced [3].

Perhaps most worrisome, regardless of whether a particular location is licensed, CPCs engage in counseling that is misleading or false [8]. Despite claims to the contrary, these centers do not meet the standard of patient-centered, quality medical care [18]. The counseling provided on abortion and contraception by CPCs falls outside accepted medical standards and guidelines for providing evidence-based information and treatment options. For example, CPCs often suggest a link between abortion and subsequent serious mental health problems [3], while multiple studies have invalidated this assertion [19-21]. Similarly, centers cite debunked literature showing an association between abortion and breast cancer [22]. Although abortion has been shown to be safer than childbirth [23], it is portrayed as a dangerous or even deadly procedure [7].

Contrary to the claim that many CPCs make that they provide comprehensive services and offer women “all options,” most of these centers do not provide comprehensive women’s reproductive health care, abortion care, or referrals for abortion [1, 3]. For example, CPCs tend to avoid discussion of contraception and dismiss the role of condoms in preventing sexually transmitted infections [24].

### **Are Crisis Pregnancy Centers Legal?**

The question of whether CPCs are “legal” is complicated. Centers lack regulatory oversight as they are not medical practices and do not charge for services. This exempts them not only from laws and statutes specific to medical clinics but also from Federal Trade Commission or state regulations that apply to commercial enterprises. Their practices are considered to fall under the classification of free speech, which is protected by the First Amendment [2, 11]. This makes them much harder to regulate and provides

them with a loophole to avoid scrutiny while providing information that does not conform to medical standards of care.

Multiple, largely unsuccessful legal challenges have been brought against CPCs, mainly in the form of local ordinances that require them to disclose that they are not medical centers and that they do not refer for abortion [4, 9]. One notable exception is the Reproductive FACT Act in California, which requires CPCs to offer information on where clients can obtain a full scope of low-cost or free reproductive health services. CPCs without a physician on staff must also disclose their unlicensed status [13]. This law was upheld by the Ninth Circuit Court of Appeals in October 2016 [13], but it is likely to be heard before the Supreme Court in March 2018 [25]. A ruling by the Supreme Court in favor of CPCs could definitively hamper efforts to curb deceptive practices by considering them free speech. This would be unjust because of the harms to women incurred by inaccurate information provision and by an organization's noncompliance with regulations such as HIPAA. Seeking abortion is time-sensitive; providing inaccurate information causes delays that can lead to higher costs and risks or even an inability to receive care [8]. The safety and well-being of women seeking abortion or any reproductive health care should take precedence over free speech, particularly when exercising that right can harm patients.

In stark contrast, despite receiving no federal and often no state funding [26], abortion clinics face increasingly high legal barriers [11]. Abortion clinics are strictly regulated, and abortion practice is often restricted by waiting periods, gestational age limits, and targeted regulation of abortion providers (TRAP) laws [11, 27]. Moreover, several states require medically inaccurate scripts and counseling that fail to protect free speech for abortion providers [27]. In North Carolina, where we practice, the state requires directed counseling, and informed consent must be given 24 hours prior to an abortion procedure [28]. This mandated counseling includes information on how women can see real-time images of the fetus and hear the heartbeat through an agency that provides this service for free; in other words, health care professionals must let women seeking abortion know about the existence of CPCs.

### **Are Crisis Pregnancy Centers Unethical?**

Because CPCs purport to offer medical advice and care, it seems reasonable to expect them to abide by medical ethical principles. Four fundamental principles are widely recognized as guides to practice: beneficence, nonmaleficence, respect for autonomy, and justice [29]. Beneficence requires that treatment and care do more good than harm; that the benefits outweigh the risks, and that the greater good for the patient is upheld [29]. Providing inaccurate and misleading information violates the principle of beneficence because it is not patient-centered and does not fully consider the patient's well-being. Anti-abortion ideology thus supersedes the needs, values, and preferences of the woman seeking care. Respect for autonomy is similarly not expressed, because a

key component of autonomy is having the information needed to make an informed decision and the ability to make medical decisions free of coercion. Again, by placing ideology over accurate and comprehensive counseling, CPCs violate respect for a woman's autonomy by failing to give her the tools necessary to make the decision that is best for her life and circumstances [3].

Nonmaleficence, or the idea that health care professionals should "do no harm," is violated in multiple ways by CPCs. First, because these centers might tell women they have "plenty of time" to get an abortion, they could delay access to abortion, which could lead to women missing the gestational age cut-off for abortion in a given state; expose women to more involved and slightly riskier procedures at higher gestational ages; or cause women to miss the opportunity for abortion altogether [8]. Second, false or misleading information about contraception, condoms, and abortion could lead to unnecessary anxiety or failure to use measures that protect against sexually transmitted infections [24].

From a public health standpoint, these centers endanger women by misinterpreting and misrepresenting medical evidence. States implicitly endorse these centers when they provide support for them. Women are put in a difficult position when they have to navigate a perplexing landscape: abortion is safe and legal in every state, yet some states support and promote centers that provide inaccurate information on abortion. These conflicting messages presume a level of sophistication on the part of patients—that they understand the political landscape that underlies the abortion debate and that they are able to make informed, autonomous decisions despite the misinformation that they are given [11].

Distributive justice assumes a fair distribution of resources. In the setting of CPCs, justice is violated when women are not apprised of the availability of abortion services and access to abortion is consequently obstructed. Moreover, CPCs often target low-income women and women of color, adolescents, and women with less formal education [3, 12]. By [impeding access](#) to abortion through delays, expense, or other tactics, CPCs may propagate racial, ethnic, and socioeconomic inequities [12]. Multiple factors contribute to women's seeking to terminate a pregnancy, including economic considerations, the need to parent other children, relationship factors, professional aspirations, and educational goals [30, 31]. Those who are unable to obtain an abortion might be less likely to have and achieve aspirational goals, which affect overall well-being, and are exposed to the greater health risk of carrying a pregnancy to term [23, 32].

What are the ethical obligations of CPC personnel? CPCs are often staffed by lay volunteers [13], but many have volunteers who are licensed medical professionals such as nurses, physicians, and ultrasound technicians [1]. Even in their capacity as volunteers, health care professionals should conform to the ethical standards guiding

their profession. It is less clear what the standards for providing ethical care should be for lay volunteers. However, given that the federal government and 14 states fund CPCs [13], taxpayers should expect that all volunteers adhere to accepted medical ethical standards when providing health care advice.

### **Towards a More Ethical Approach**

As nonprofit organizations, CPCs have the right to exist. Indeed, they could provide a valuable resource for some women, particularly those seeking material support for a pregnancy they plan to continue [33]. However, as we have seen, they also employ dubious communication strategies— withholding information about abortion referral, not being transparent about clinically and ethically relevant details, or using inflammatory language to scare women and dissuade them from having abortions [3, 8, 9].

Honest information about the perspective from which they dispense advice and support, in addition to forthright acknowledgement of their limitations, is essential for these centers to provide an ethical service to women. For no other medical procedure would someone who is not a health care professional seek to give detailed counseling on the risks of the procedure. CPCs should provide clear advertising and refrain from providing misleading and false information about abortion. Clear acknowledgement that no abortion referrals will be made would also be a step in the right direction. Until taxpayers can be assured that these centers conform to ethical standards of licensed medical facilities, offer sound medical advice, and do not lead to harm, states should refrain from directly or indirectly funding these centers.

Finally, health care professionals should be aware of the existence of CPCs and alert to the harms they can cause. Because primary care physicians who encounter pregnancy diagnoses may not be comfortable with options counseling [34], they should educate themselves about where women can obtain comprehensive reproductive health care locally to avoid referrals to CPCs for women considering abortion. Health care professionals also should support laws, like California's, that regulate CPCs by preventing them from withholding critical information about abortion availability from women seeking abortion.

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## POLICY FORUM

### Who Counts? What Counts? Place and the Limits of Perinatal Mortality Measures

Claire Wendland, MD, PhD

#### Abstract

Maternal and neonatal mortality statistics foreground some possible causes of death at the expense of others. Political place (nation, state) and place of birth (hospital, home) are integral to these statistics; respect for women as persons is not. Using case examples from Malawi and the United States, I argue that the focus on place embedded in these indicators can legitimate coercive approaches to childbirth. Qualitative assessments in both cases reveal that respectful care, while not represented in current indicators, is critical for the health of women and newborns. Perinatal outcomes measures thus must be rethought to ensure ethical and safe maternity care. This rethinking will require new questions and new methods.

#### Introduction

Public health experts say that what counts is what you count. Health statistics draw attention to certain problems. They shape policies and interventions. They determine funding streams. They connect health outcomes to other factors—often implying causal linkages—and so they matter not just for our measures of suffering but for our explanations of why it occurs. Indicators like mortality rates illuminate certain aspects of birth, life, sickness, and death—for instance, where these events happen. They also obscure other important aspects—for instance, whether a woman is treated with respect, or whether she is subject to the injuries of racism and sexism. I will briefly describe problems with the selection and use of perinatal health indicators, illustrate the focus on political place (nation, state) and place of birth (home, hospital) that they entail, discuss their limits, and explain why what we count and don't count matters, clinically and ethically.

In the two nations in which I've practiced obstetrics and witnessed the deaths of mothers, Malawi and the United States, maternal and neonatal mortality indicators are limited by infrastructure and shaped by bureaucratic processes. In both nations, statistics can push policymakers and clinicians to focus narrowly on the place of birth—specifically, whether birth happens inside or outside a clinical facility—and in so doing to neglect other factors vital to the well-being of mothers and their newborns. I argue that maternal and neonatal mortality statistics can be misused to support policies and

practices that restrict women’s autonomy. Exclusive attention to such statistics can also lead to misplaced attributions of responsibility for poor maternal and newborn outcomes and thus work against reproductive justice by further marginalizing certain groups of women while shielding powerful institutions from blame.

### **Making Numbers**

Let’s begin with the indicators used to measure maternal death (see table 1). In Malawi, while death rates are thought to have improved recently, they still appear very high: a woman’s lifetime chance of dying from a maternal cause is estimated at 1 in 29 [1]. In the United States that odds estimate is 1 in 3,800 [1], but maternal death rates seem to be increasing substantially—in sharp contrast to all other wealthy nations and most poor ones [2].

**Table 1.** Comparison of Malawi and the United States on selected perinatal mortality indicators, 2015 [1, 3]

Perinatal mortality indicator	Malawi	United States
Maternal mortality ratio <sup>a</sup>	634	14
Lifetime risk of maternal death	1:29	1:3,800
Neonatal mortality rate <sup>b</sup>	23.1	3.7

*Note:* 2015 indicators are the most recent indicators available.

<sup>a</sup> Maternal deaths per 100,000 live births

<sup>b</sup> Deaths in first 28 days of life/1,000 live births

Use of the words “seem” and “appear” is important in the prior sentences. These indicators are numbers that can easily look like facts, but maternal mortality statistics are notoriously uncertain [4]. The most significant source of uncertainty is underreporting: underreporting of maternal mortality is common worldwide, especially for late maternal deaths (such as those caused by thromboembolic events, for which the risk remains elevated several months after delivery) and for deaths resulting from stigmatized causes (such as complications of illegal abortion) [4, 5].

Comparison of the two nations’ mortality rates, presented in table 1, requires mathematical artifice. In other words, these numbers that take similar forms come from completely different original data sources and collection practices and go through completely different bureaucratic procedures and mathematical transformations. Place matters, not for death alone, but for the production of numbers about it.

In most relatively wealthy countries, including the United States, maternal deaths are counted from death certificates recorded in civil registration systems. Death certificate

formats, data recording, and data collection practices in the United States vary from state to state. Most states include a box for indicating whether the dead person was or had been recently pregnant. However, instructions for checking these boxes vary, and the implementation of check-boxes at different times in different states makes calculations of nationwide maternal mortality so unwieldy that, actually, no official US maternal mortality ratio has been reported since 2007 [2]. Epidemiologists typically use computerized records to aggregate data from sources that vary state by state and then multiply these data by “correction factors” to adjust for different reporting practices or suspected underreporting [1, 2]. These adjustments are appropriate and necessary. They contribute to confusion surrounding maternal mortality, however, as both uncorrected and corrected statistics circulate and experts debate how corrections should be made.

In Malawi and in most other poor nations, the places where the great majority of the world’s maternal deaths actually happen, mortality rates are modeled estimates rather than adjusted counts [5]. Infrastructure problems mean that neither paper death certificates nor computerized records are gathered reliably into a central vital registration system. By some estimates, three-quarters of Malawi’s deaths are never officially reported [6]. Instead, maternal mortality is estimated from samples of Malawi residents who are surveyed about the lives and deaths of their adult siblings. This approach, the “sisterhood method,” is an important innovation that sprang from a realization that families often knew what health systems and state bureaucrats did not [7]. Sisterhood data is then transformed by a complex model designed to adjust for likely sampling and reporting errors, a model that is contentious and that has changed over the years [8].

In both countries, a great deal of uncertainty is ultimately hidden in a number—such as a maternal mortality ratio—that looks like a fact. (Because maternal deaths are relatively uncommon even where they are nowhere near rare enough, underestimating or misattributing even a few deaths makes a large difference in the maternal mortality ratio. Statistics used to track newborn and infant deaths, which are more common and less vulnerable to misattribution, have much narrower uncertainty ranges.) The many uncertainties of measurement and estimation mean that country-level maternal mortality statistics reported by the World Health Organization (WHO), by other transnational organizations, and by national ministries or departments of health often vary substantially; in extreme cases, they can vary by a factor of two or three [4, 5]. Such variation can generate distrust of the numbers. For example, Malawian physicians with whom I recently spoke, while agreeing that maternal mortality in their country was a serious problem, dismissed reported maternal death statistics as “just political” (oral communication, July 2017). Maternal health epidemiologists and advocates working in global health worry that uncertainty about maternal mortality statistics leads donors to avoid investments in improved maternal health in favor of other kinds of interventions whose effectiveness can reliably be assessed in terms of lives saved per dollar invested [4]. The uncertainties of maternal mortality measures have real effects that can hurt

[maternal health](#). The numbers themselves also have profound effects.

### **Ethics, Choice, and Place**

If ethics is about what should (and should not) be, and statistics claim to be about what is, why do mortality indicators matter ethically? One reason is that statistics can help delineate boundaries of ethical concern: indicators like maternal mortality are nearly always reported at the national level, and, implicitly, responsibility for women's health and deaths is then placed within the borders of a nation. The realities of life, death, politics, and infrastructure rarely stop at national borders, however; both larger and smaller social divisions matter for who lives, who dies, and who takes the blame.

Place also gets embedded in measures of maternal and perinatal mortality that include delivery location, which then becomes a focus for policymakers. Place of delivery is generally specified as either inside or outside a hospital. It is included on birth certificates in the United States and can readily be linked by epidemiologists to death certificate data [9]. In Malawi, it is one of the indicators calculated from survey samples [10].

All United Nations member states pledged in 2000 to work toward a series of goals that would indicate greater well-being for people worldwide; one of those goals was to reduce maternal mortality by 2015 to one-quarter of its 1990 levels [11]. In Malawi, frustration with an apparent lack of progress on maternal mortality as the 2015 deadline drew near led politicians to focus on ensuring that women gave birth in health care facilities rather than in their homes or at the clinic of a traditional birth attendant [8]. Facility birth, unlike maternal mortality, was relatively easy to measure and to influence. Government leaders implemented policy changes and community-education efforts designed to move birth out of homes and into hospitals and other health facilities. These efforts often became coercive [12]. A Malawian woman can now be fined for giving birth outside the hospital; her decision to do so is taken as an indication of recklessness, ignorance, or both [12]. Many out-of-hospital ("traditional") birth attendants were taxed with substantial fines, and some were threatened with imprisonment. Yet punitive measures against out-of-hospital birth were not supported by clear evidence that facility birth in Malawi produced better health outcomes. Nor were they accompanied by the large increase in trained staff, the improvement in medical and pharmaceutical supply systems, or the development of infrastructure that would likely have been needed to keep women safer *inside* hospitals [12, 13]. Women were pushed, threatened, and shamed into facilities that lacked staff, essential supplies, electricity—sometimes even soap and water.

In the United States, the numbers of women who give birth at home are too small to hazard a guess about how (or whether) maternal mortality and place of birth are linked. However, concerns about outcomes for newborns, in many cases supported by neonatal health indicators, have led to paternalistic and punitive policy stances and even

proposals to make out-of-hospital birth illegal [14]. One group of perinatologists, for instance, has repeatedly advocated in a mainstream obstetrics journal that obstetricians who consult with out-of-hospital practitioners or even support research on home birth should be sanctioned by their professional boards [15]. This group has argued that pregnant women have the right only to make choices that entail no risks to a fetus and the ethical obligation to do what their obstetricians think best [14, 15].

Professional organizations of obstetricians and midwives have pushed back, and women in the United States can still legally [give birth at home](#)—although financial obstacles, lack of insurance coverage, and limited access to well-trained birth attendants often make it difficult. However, women who choose to give birth at home can also be shamed for doing so regardless of birth outcomes, as a review of comments on any online home-birth discussion will quickly show. The shaming is not only from internet “trolls.” In a statement on home birth, the American College of Obstetricians and Gynecologists blamed women for “plac[ing] the process of giving birth over the goal of having a healthy baby,” and implied that decisions to avoid hospital birth were frivolous by proclaiming that “childbirth decisions should not be dictated or influenced by what’s fashionable, trendy, or the latest cause célèbre” [16]. Moreover, physicians have been known to make referrals to child protective services based on a woman’s choice to give birth at home [17]. Like other coercive reproductive interventions, such as court-ordered cesarean delivery, actions like these constrain women’s autonomy—and they are often grounded in highly selective readings of neonatal outcome indicators [14].

In both Malawi and the United States, then, perinatal statistics are used to create and reinforce a sharp distinction drawn between the inside and outside of the formal health sector. The inside is drawn as good, safe, and the responsible choice; the outside is bad, dangerous, and recklessly chosen. That distinction is in turn the justification for implementing paternalistic restrictions on women’s autonomy, whether through legal measures, [shaming](#), or claims about mothers’ ethical responsibilities to submit to clinical authority. In both countries, a narrow focus on place of birth allows policymakers, clinicians, and public health professionals to blame women for their own or their newborns’ deaths and, in so doing, pay little attention to the reasons women might want to (or have to) avoid giving birth inside hospitals. A Malawian woman might elect not to brave the dirt paths that connect her village to the nearest health facility—paths that are unsafe after dark—when her labor begins. Or she might seek to avoid rude treatment, inadequate staff, or informal charges for supplies and medication [18]. If she does so, whatever happens “at home” will likely be regarded by some as her fault. An American woman might elect a home delivery rather than brave the high cesarean rate and iatrogenic pathogens at her local hospital. If she does so, she will likely be blamed for any harmful consequences to herself or to her infant [16]. Health indicators can underwrite infringements on women’s autonomy and allow professionals and policymakers to overlook conditions in which women labor and give birth inside

hospitals. Sometimes these conditions are aversive. Sometimes they are lethal.

### **Looking Beyond Statistics**

Perinatal indicators are important. It is the exclusive reliance on statistics that exclude women's experience, not their existence, that is the problem. It's not the tracking of maternal mortality in the United States or the ever-more-sophisticated modeling of it in Malawi that hurts women. The contrast between what statistics can uncover and what we can learn from other kinds of investigation is instructive, however. Death-certificate data often lead to a narrow focus on medical diagnoses and bodily pathologies rather than broad attention to the harms of poverty, inequality, racism, and misogyny. Sample surveys like those used in Malawi are probably more effective at measuring socioeconomic status and less effective at assessing pathology, but they too conceal the impact of low-quality or disrespectful medical care. Statistics currently used in Malawi and in the United States do not measure the effects of callous treatment, fragmented health care, or moral and political climates that undercut family support and gender equity.

The lack of attention to these aspects of women's experiences is a serious omission. Qualitative research in Malawi, including my own ethnographic work, has shown that in some cases women deliver alone or in unsafe conditions rather than face rudeness, neglect, or delays in health facilities [12, 13, 18]. In the United States, qualitative investigations by a journalism team revealed patterns that do not appear in standard perinatal indicators but that nevertheless matter for our understanding of why women die [19, 20]. Women who experienced "near misses" (that is, who almost died but didn't) and family members of women who died very often told the reporters that distracted, overstretched nurses and doctors simply did not listen to them or pay attention to their concerns [21]. Health professionals were particularly likely to disregard the worrisome symptoms of black women [22]. Meanwhile, many of the physicians and nurses who spoke with reporters noted that a professional focus on fetal and newborn well-being, including newborn outcomes measures used to accredit hospitals, had led medical teams to pay less attention to the needs of mothers [20, 23].

Social scientists and historians have argued that public health indicators don't simply represent a reality "out there." They create realities, too, at least in part by helping people marshal support for some policies and practices. To cite a historical example, in late-1940s Britain, neonatal mortality rates were used to support the patriarchal social status quo; obstetricians and pediatricians claimed that a woman's primary obligation was to her home, an obligation on which the survival of her children depended [24]. In this article I have argued that in both Malawi and the United States, a contemporary focus on indicators such as maternal mortality ratios, proportions of facility births, and neonatal mortality rates has arguably contributed to medical and public health initiatives that overemphasize place and underemphasize respectful, attentive, and knowledgeable

care. Such initiatives restrict women's agency, limit women's exercise of autonomy, and undermine reproductive justice.

### **New Questions, New Methods, Next Steps**

In 1962, pediatrician C. Henry Kempe published an article explicitly naming child abuse as a problem. By gathering together concerns that had previously been diffuse under a specific label, he made possible new methods to measure, analyze, and intervene in child abuse [25]. It is hardly conceivable to most of us now that in 1961 the crucial concept of child abuse simply did not exist. In 2003 social epidemiologist Nancy Krieger posed the explicit question: Does racism harm health [26]? Many previous studies exploring race-based disparities in health had built in assumptions that race could stand in for some form of biological difference. By naming racism, *not race*, as a possible pathogen and subject for investigation, Krieger opened the door for new measurement techniques that combined quantitative and qualitative approaches. The answer quickly became clear: racism—structural and interpersonal—has profound health effects [27].

We are in a moment in which it is ethically incumbent on women's health professionals and public health experts to ask whether sexism—structural and interpersonal—endangers women. Asking this question is critical. Answering it will likely require the courage to rethink standard models of gathering and processing data and the willingness to combine quantitative and qualitative approaches [28]. It is a serious error of both ethics and public health to rely solely on statistical methods that presume women's experiences to be irrelevant or unmeasurable, that make it convenient to blame women for their own deaths, or that exclude assessments of deep structures of inequity. To continue in our present course, presuming that only what is countable counts, limiting our analysis to what is easily rendered into current statistical measures, is to fail women and families profoundly.

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## MEDICINE AND SOCIETY

### When Should Screening and Surveillance Be Used during Pregnancy?

Nancy D. Campbell, PhD

#### Abstract

Using the ethical and legal concept of shared responsibility for healthy births, this article considers social, cultural, and historical contexts in which medicalization and criminalization have worked in tandem to widen surveillance in ways that intensify scrutiny of women's lives under the guise of child protection, bringing women who are pregnant, postpartum, or parenting under criminal justice control. Although pregnant and postpartum women are prime candidates for medication-assisted treatment (MAT), the expanding carceral system has not prioritized drug treatment or reproductive justice. This article investigates ethical and historical dimensions of the question, According to which principles and practices should screening and surveillance be carried out to reduce harm, safeguard civil and human rights—including reproductive autonomy—and ensure that treatment, when necessary, occurs in the least coercive settings possible?

#### Introduction

I could not believe my eyes: "Mom Is Part of the Cure for Tiny Opioid Victims" read the front page of the *New York Times* and, beneath the title, "Doctors Say Cuddling with Infants Helps Ease Withdrawal" [1]. Amnesia and ignorance pervade the topic of drug-using pregnant women, who have experienced increasing clinical surveillance within a culture that blames pregnant women for exposing "tiny opioid victims" to health risks such as neonatal abstinence syndrome (NAS). Was "Mom" to be at long last recognized as part of the solution to a problem for which cure has been elusive and compassion limited? Alas, the situation recounted in the article did not bear out the optimistic headline.

Women who use opioids or illicit drugs continue to be threatened with punishment rather than being met with supportive treatment designed to inculcate shared responsibility for healthy births. Despite reasoned opposition to punishing pregnant women from all major medical and public health organizations [2], illicit drug-using women remain vulnerable to disdain, discrimination, and criminal prosecution in the United States particularly when pregnant and seeking hospital-based delivery [2, 3]. Although surveillance has been undertaken for purposes of criminalization of pregnant

women in punitive contexts, willingness to prosecute pregnant drug-using women has varied by region and social location [4, 5]. If healthy births and breastfeeding are the desired outcomes, surveillance and reporting should support those goals rather than providing an entrée into the criminal justice system.

Clinical practitioners should screen and surveil pregnant and recently postpartum women *only* for purposes of supporting their health and safety as patients. In criminal justice contexts, diagnostic screening and surveillance technologies have been speculated to deter women from using drugs, but some uses of these technologies have been demonstrated instead to deter women from seeking prenatal care and even medical assistance in childbirth [6]. Decisions to carry a pregnancy to term are dramatically constrained in the population of drug-using women, which is highly heterogeneous. However, once a woman has decided to carry to term, healthy birth outcomes become a responsibility shared between the pregnant woman and her team of health care practitioners. Whereas biomedical surveillance may be used to provide better care and more accurate diagnosis and to reduce risk, it should also be borne in mind that surveillance has historically been deployed in ways that augment harm, detract from care, and increase risk.

### **History of Surveillance of Opioid Drug-Using Women**

At the turn of the twentieth century, the typical US “addict” was a respectable white woman maintained by physicians on morphine [7]. Physicians knew how to taper off babies born to such women—who were pitied but viewed as nonthreatening—through the clinical practice of morphine maintenance. During a brief period following the passage of the Harrison Narcotics Tax Act in 1914, municipal clinics in many states dispensed morphine to those registered to receive daily doses [7]. The act, which is still in effect, regulates the production, import, and dispensing of opium and coca products [8]. Its early enforcement consequently led to the prosecution of thousands of physicians for maintaining patients on morphine [7].

Over the next three decades, the demographics of the opioid-addicted population changed. In the 1930s, this population was largely white and male aged 45 and older. During that time, the National Research Council Committee on Drug Addiction set out to identify substitutes for each of the “indispensable uses of morphine” so as to minimize its use [9]. Large-scale demographic shifts occurred after World War II as illegal drug markets burgeoned in urban communities of color [10]. Postwar heroin addicts were younger, poorer, and more often black or Puerto Rican than their forebears [10]. The 1950s also witnessed the first mandatory minimum sentences for drug crimes. In response, a cadre of progressive doctors and lawyers formed an American Medical Association (AMA)/American Bar Association (ABA) Joint Committee that in 1961 released a controversial report, *Drug Addiction: Crime or Disease?*, advocating morphine maintenance in the face of prohibitionist policy [11].

Caught up in these shifting patterns, women trickled into the ranks of the addicted; both pregnancy and addiction became symptoms of gendered psychopathology in the studies of the 1950s [12]. An early epidemiological study, *The Road to H*, explained that unlike men and boys, “females have available to them another technique of ‘acting out’ ... which is not available to males, namely, the out-of-wedlock pregnancy,” a drama “enacted largely in the life of the female” [13]. Women were asked little about their experiences of pregnancy, birth, child removal, grief, and loss; archival and anecdotal sources confirm their lack of agency in these decisions. An enduring pattern took hold along color lines in which white women who used illicit drugs or became pregnant out of wedlock were diagnosed with personality disorder and mental illness, whereas similarly situated women of color were labelled “sociopathically disturbed,” “deviant,” and “criminal” [12, 14-16].

Women’s reproductive decisions and practices periodically came under state and social scrutiny, but pregnant drug users came to very little notice until neonatologists began to see babies born to “heroin mothers” in the late 1960s. By this time, the combined lack of medical education about drug dependence—including detoxification techniques used in babies born to opioid-dependent women—and continuing prosecution meant that most clinicians knew little about addiction and were understandably reluctant to deal with a patient who was a “dope fiend” [17]. In *Robinson v California* (1962), the US Supreme Court cited the paucity of medical literature on addicted babies [18], a medical terrain that was charted anew later in the 1960s. A 1958 study had listed signs of neonatal withdrawal: hyperactivity, trembling, twitching, convulsions; shrill, high-pitched, prolonged cry; and an “almost constant sucking and chewing on the hands and fingers as if hungry” [19]. A 1966 study at Metropolitan Hospital in New York City study found that addicted women averaged less than one prenatal visit per pregnancy; slightly more than 40 percent experienced obstetrical complications; and 20 percent left the hospital early [20]. As to these mothers, most were “unconcerned with prenatal care” [21]:

She lives in conditions of poverty, her diet is poor, and she is liable to venereal disease and a multitude of infectious diseases.... Not only is her physical condition poor, but also she cares nothing about improving it as long as she can obtain enough heroin to stave off withdrawal symptoms and to give her the occasional lift above the conditions in which she lives [22].

Babies born to these mothers were immediately adopted out, treated by clinicians who had received no training on the specifics of maternal-fetal or neonatal abstinence despite rising numbers of babies born with “narcotic addiction” [23]. In response, physician Loretta Finnegan and colleagues identified neonatal abstinence syndrome

(NAS) and initiated a maternal education program, drawing attention to the health issues of drug-using women and their babies around the world [24].

The 1970s was an era of widening availability of reproductive health care and methadone maintenance, which had become standard treatment for opioid-dependent people by the 1980s [25]. However, this expansion drew ire from those proposing coercive measures such as mandatory treatment or compulsory commitment to control addicted women who became pregnant [26]. A politically adversarial discourse of the “unborn child” arose in the drug treatment arena. As Densen-Gerber, Wiener, and Hochstedler observed, “Unfortunately, there is at present no legal means of controlling the behavior of the pregnant addict in the interest of the unborn child” [26]. The authors advocated “narrowly drawn, closely defined statutes in every state providing for compulsory commitment and treatment of pregnant addicts for the duration of the pregnancy” [26]. Such views intensified with the advent of crack-cocaine in the late 1980s, when drug-using women’s “decline of maternal instinct” became subject to Congressional hearings and surveillance invaded health care [27]. Right-wing activism around fetal personhood and “unborn victims” of drug-using pregnant women harnessed medicalization of maternity to the criminalization of addiction.

The medicalization of maternity with respect to opioid-dependent women also took progressive form during the 1990s, when some physician-researchers who treated opioid-dependent pregnant women began using the intake and assessment process to build a “therapeutic alliance” [28]. National Advocates for Pregnant Women (NAPW) enrolled many medical and public health practitioners and organizations, arguing against [punitive reporting and criminalization](#) all the way up to the US Supreme Court [29]. Yet medicalization and criminalization have long been intertwined, with the emphasis shifting from one to the other depending on which social locations and user populations were perceived to foster problematic drug use.

### **Medication-Assisted Treatment as a Special Need for Pregnant and Postpartum Women**

States that do not provide the full range of reproductive health care often do not provide the full range of drug treatment services, an observation suggesting that the evidence base for both is being ignored. Access to [medication-assisted treatment](#) (MAT) for opioid dependence, which currently includes methadone maintenance therapy and the promising new partial agonist-antagonist buprenorphine [25], often has limited availability in the very places where opioid problems abound. These include criminal justice contexts where access to MAT has been particularly uneven and forced abstinence is common [30]. Despite abstinence being considered the cornerstone of recovery, I maintain that abstinence is also a risk factor for overdose and thus for overdose death; a pregnant woman’s abstinence places the fetus she is carrying in a “risky situation.” Social contexts in which women use drugs or associate with known

drug users, producers, or distributors are understood as risky. Risks are compounded in cases in which abrupt abstinence from opioid agonists place pregnant women and the fetuses they carry in harm's way. On the other hand, MAT is protective for pregnant women and the fetuses they carry.

Yet women on MAT have been denied not only medication but also compassionate care and humane treatment during detention, enduring dangerous withdrawals while detained by the criminal justice system [29, 30]. Despite the unethicity of this practice, which withholds a known effective treatment, pregnant women themselves are often viewed as "endangering" the fetus when they are identified as drug users [31]. Given the negative consequences and ethical implications of identifying women as drug users, Terplan and Minkoff warn against simply advocating universal voluntary screening to detect prenatal drug use as a technological fix that does not address the broader social and economic contexts in which pregnant women use illicit drugs [31].

In *Using Women: Gender, Drug Policy, and Social Justice* [16], I argued against heightened scrutiny into drug-using pregnant women's lives even on grounds of "protecting the unborn" [32] or "doing what's best for baby." In the midst of what Mayes et al. called the "rush to judgment" about crack-cocaine-using pregnant women [33], I adopted feminist-legal theorist Dawn Johnsen's promotion of the concept of shared interest in "promoting healthy births" [34]. In shouldering shared responsibilities with drug-using pregnant women, health care professionals should recognize the multiple stigmas that shape the lives of drug-using women's experiences of pregnancy, childbirth, and mothering and ally with them to confront a society that has rushed to judgment about who knows best what actions and decisions they are to take.

Therapeutic alliances must also address the racial politics and class inequities of the injustices that opioid-dependent pregnant women have experienced. Treatment trajectories diverge depending on the social locations of the women involved. Racial disparities influence who is able to access treatment and who is sent to prison [35]. But punitive sanctions serve only to deter women from seeking prenatal care, a point consistently made by every major professional organization dealing with pregnancy and addiction [2-4]. Such statements are regularly compiled and updated by NAPW, one of few organizations equipped to take on cases in which pregnant and parenting women are charged with crimes in the course of living out their lives [2, 3, 29].

Ethics in the kinds of risky situations described above is not a mere preoccupation with abstract principles—nor should ethics be understood as limited to technical details. Ethics is practical, often arising as a result of specific cases with particular histories of harm and injustice. Enjoined to do no harm, physicians arguably have a duty to reduce harm and certainly to provide care that does not coerce, stigmatize, or criminalize.

Physicians share responsibility to ensure access to the full range of reproductive health care and drug treatment for their patients who need it. Physicians also share with drug-using pregnant women responsibility to bring about healthy births and humane treatment for all concerned—mothers, babies, and children. Ensuring access to the full range of evidence-based drug treatment should be considered part of these affirmative duties. Biomedical surveillance should be conducted only for clinical purposes having to do with ensuring access to and delivering quality health care. Just because we have surveillance technology does not mean we should use it against the very women who need to be enrolled in caring for their infants. “Mom” is part of the cure, and compassionate care demands that surveillance be judiciously used in therapeutic spaces.

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## SECOND THOUGHTS

### Should Race Be Used as a Variable in Research on Preterm Birth?

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#### Abstract

Racial variations in preterm birth (PTB) outcomes are well described, but causal mechanisms linking race and PTB are not. In clinical research, race is typically treated as representing fixed biological traits. In reality, race is a social construct that approximates lived experiences of historical and ongoing systematic discrimination and, in the case of PTB, particular stressors of black womanhood and reproduction. These experiences are embodied as adverse multigenerational health outcomes. Race thus presents a dilemma for researchers. Conflating race with genetics enacts harm, but excluding the race variable produces irrelevant research. Instead, we must consider race in an ecosocial context. PTB is fertile ground for expanding research approaches to respect the history, reality, and implications of race in the United States.

#### Introduction

In the world of perinatal medicine, significant variations in preterm birth (PTB) outcomes by race are well described. Despite gains in other areas of [perinatal morbidity](#), black women in the United States give birth to 48 percent more infants preterm (at less than 37 completed weeks of gestation) than all other women [1]. Between 2012 and 2014, 13.3 percent of US black infants were born preterm compared to 9 percent of white infants [1]. What remain poorly characterized, however, are the causal mechanisms that link race and PTB.

Most biomedical research employs a conception of race as an individual, fixed trait that promotes or reduces disease through biological pathways [2, 3]. Historically, researchers in the biological sciences sought to explain differences in PTB rates between black and white women using differences found at the individual level: maternal age, parity, body mass index, smoking status, comorbid disease diagnoses, cervical length measurement, vaginal microbiota, and history of sexually transmitted infections [4-8]. Perhaps no work is more representative of this approach to PTB studies than those measuring the association between variations in maternal genotype and the risk of spontaneous PTB [9-12].

A focus on organic, biological differences between cohorts is not unexpected in the biological sciences, of course. However, race is not inherently biological. Genetic variation between humans of different “races”—that is, with distinct skin color and facial phenotypes—is minimal [13], and genetic racial classification techniques are inconsistent, ambiguous, based on insufficient data, and incorporate sociopolitical status designations [13]. While using race as a categorical variable in research and clinical care to identify women with high a priori risk for PTB is simple and efficient, it is critical that the variable is understood and interpreted to represent something other than a biological phenotype. In what follows, we expound upon approaches researchers might consider when interpreting race as an ecosocial variable.

### **Race and Preterm Birth**

The human classification schemas based on skin color that lay the groundwork for our contemporary racial categories emerged fully in the mid-eighteenth century [14]. They were based on assumptions predating evolutionary biology, such as Johann Friedrich Blumenbach’s theory that human variation represents a range of traits that degenerated from an original ideal “type”—people with white skin of European descent [15–18]. Specious systems of racial classification continue to be recreated through implicit and explicit legal and scientific means, establishing a framework that determines the distribution of political, economic, psychological, and social power and resources [13, 17]. As dark-skinned people of African descent were placed lowest on this enduring hierarchy, we will use contemporary black-white racial disparities to further comment on the use of race in PTB research.

PTB studies investigating either candidate genes in the metabolic and inflammatory pathways such as interleukin 6 and tumor necrosis factor- $\alpha$  [9–11, 19–21] or transgenerational PTB risk, wherein black women born very preterm are more likely to deliver their own infants very preterm [6, 22], epitomize the epigenetic link between the historical and ongoing reality of racism and embodied health outcomes. Treatment of racial designations in this research must be considered in an ecosocial context [23] because these [socially constructed](#), politically determined categories have physiologically evident, measurable, and enduring biological effects [15–17, 24]. With regard to maternal, infant, and reproductive health broadly and to PTB in particular, we must acknowledge the historical and ongoing environment in which black womanhood and reproduction occurs. This context includes social and economic repression of reproductive agency in the service of sociopolitical hierarchy—including historical conditions of enslavement, physical and psychological violence, coercion, and hypervigilance to ensure black children’s survival [25–27]. Lifetime and intergenerational exposure to such extreme environmental stressors is a well-established risk factor for preterm birth that could contribute to persistent racial disparities [28]. Proponents of the hypothesis that preconceptional environmental stress contributes to the risk of PTB explicitly call for increased multidisciplinary research in this area [28–30].

The complexities of measuring this nuanced ecosocial context prompt questions about whether we should use race as a variable at all in research. However, to exclude the variable that most accurately measures determinants of multigenerational poor infant and maternal health outcomes produces research that is not relevant to the reality of our society [31–34]. Scientific reproduction of the reductionist ideology that conflates racial categories with genetics enacts harm by reinforcing racial stereotypes and the erroneous belief in innate racial differences [18].

### **Structural Racism and Health Outcomes**

The association between race—understood as the accumulation of lifetime exposure to stressors rather than simply a genetic phenomenon—with PTB and other adverse pregnancy outcomes has been described in part by social scientists quantifying the impact of residential segregation or race-based microaggressions (indirect or unintentional discrimination against members of a marginalized group) on PTB risk, although mechanistic pathways remain poorly understood [35–37]. While this research is relatively new and limited in scope, PTB and reproductive and maternal health more broadly present opportune space in which to expand research on the [embodied effects of race and racism](#) [38–41].

Researchers in public health are producing a growing body of knowledge on how biology (genetics) and social context (the environment) interact to influence health outcomes. To draw on this emerging body of knowledge, PTB researchers can apply frameworks such as epigenetics, weathering [42], the life course [43], and stress process [44], all of which situate biological outcomes in environmental contexts—and particularly, in stressors—throughout a person’s life and across generations [23, 45]. For example, Ford and Airhihenbuwa’s Public Health Critical Race Praxis (PHCRP) is a phased conceptual approach aimed at maintaining research rigor while addressing the power structures undergirding health disparities [46, 47]. This race-conscious framework guides researchers to consider how racialization affects not only observed outcomes but also the design of studies and production of knowledge in the field. Through a set of ten principles employed in four phases, race is put into a contemporary specific context for a given research question, and investigators are challenged to identify how nonracial factors influence ostensibly racial outcomes.

### **Conclusion**

In sum, the bioethical implications of considering race in PTB research rest on the degree to which race is considered in its full context. To continue using race in biologically reductionist ways will perpetuate the racist notion that there is something inherently wrong with black bodies and black women and their capacity for reproduction in particular. This harmful reductionist thinking and practice must end. Instead, we should consider race as an approximation of the complex historical and ongoing lived experience

of systematic, institutionalized discrimination. We can integrate this framework into every phase of research—from our hypotheses, to our conceptual models, to our data analyses. Reproductive health research—and PTB in particular—is fertile ground for expanding and honing our approaches to respect the history, reality, and implications of race in the United States.

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