

## 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.

### **References**

1. World Bank. Lifetime risk of maternal death (1 in: rate varies by country). <https://data.worldbank.org/indicator/SH.MMR.RISK>. Accessed October 25, 2017.
2. MacDorman MF, Declercq E, Cabral H, Morton C. Recent increases in the US maternal mortality rate: disentangling trends from measurement issues. *Obstet Gynecol*. 2016;128(3):447-455.
3. World Health Organization. Maternal mortality. <http://apps.who.int/gho/data/node.sdg.3-1-viz?lang=en>. Accessed October 25, 2017.
4. Storeng KT, Béhague DP. "Guilty until proven innocent": the contested use of maternal mortality indicators in global health. *Crit Public Health*. 2017;27(2):163-176.
5. Mathers C, Boerma T. Mortality measurement matters: improving data collection and estimation methods for child and adult mortality. *PLoS Med*.

- 2010;7(4):e1000265.  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2854121/>. Accessed January 23, 2018.
6. Singogo E, Kanike E, van Lettow M, et al. Village registers for vital registration in Malawi. *Trop Med Int Health*. 2013;18(8):1021-1024.
  7. Graham W, Brass W, Snow RW. Estimating maternal mortality: the sisterhood method. *Stud Fam Plann*. 1989;20(3):125-135.
  8. Wendland CL. Estimating death: a close reading of maternal mortality metrics in Malawi. In: Adams V, ed. *Metrics: What Counts in Global Health*. Durham, NC: Duke University Press; 2016:57-81.
  9. Mathews TJ, Driscoll AK. Trends in infant mortality in the United States, 2005-2014. Hyattsville, MD: National Center for Health Statistics; 2017. NCHS data brief 279. <https://www.cdc.gov/nchs/data/databriefs/db279.pdf>. Accessed January 23, 2018.
  10. National Statistical Office; ICF. *Malawi Demographic and Health Survey, 2015-16*. <https://dhsprogram.com/pubs/pdf/FR319/FR319.pdf>. Published February 2017. Accessed January 23, 2018.
  11. World Health Organization. *Health and the Millennium Development Goals*. Geneva, Switzerland: World Health Organization; 2005.  
[http://www.who.int/hdp/publications/mdg\\_en.pdf](http://www.who.int/hdp/publications/mdg_en.pdf). Accessed January 18, 2018.
  12. Banda EC. *Stakeholders' Perceptions of the Changing Role of Traditional Birth Attendants in the Rural Areas of Central West Zone, Malawi: A Mixed Methods Study* [dissertation]. Johannesburg, South Africa: University of Witwatersrand; 2013.
  13. Wendland CL. Legitimate care, dangerous care, and childbirth in an urban African community. In: Olsen WC, Sargent CF, eds. *African Medical Pluralism*. Bloomington, IN: Indiana University Press; 2017:244-260.
  14. Wendland CL. Exceptional deliveries: home births as ethical anomalies in American obstetrics. *J Clin Ethics*. 2013;24(3):253-265.
  15. Chervenak F, McCullough LB, Brent RL, Levene MI, Arabin B. Planned home birth: the professional responsibility response. *Am J Obstet Gynecol*. 2012;208(1):31-38.
  16. American College of Obstetricians and Gynecologists. ACOG statement on home births [news release]. Washington, DC: February 6, 2008. *Medscape*. July 20, 2010. <https://www.medscape.com/viewarticle/725383>. Accessed January 23, 2018.
  17. Diaz-Tello F, Paltrow L. NAPW working paper: birth justice as reproductive justice. January 2010 draft.  
<http://advocatesforpregnantwomen.org/BirthJusticeasReproRights.pdf>. Accessed November 30, 2017.
  18. Kumbani L, Bjune G, Chirwa E, Malata A, Odland JØ. Why some women fail to give birth at health facilities: a qualitative study of women's perceptions of perinatal care from rural Southern Malawi. *Reprod Health*. 2013;10:9. <https://reproductive-health-journal.biomedcentral.com/articles/10.1186/1742-4755-10-9>. Accessed



October 25, 2017.

19. *Lost Mothers: Maternal Mortality in the US*. NPR. <http://www.npr.org/series/543928389/lost-mothers>. Accessed October 20, 2017.
20. Martin N, Cillekens E, Freitas A. Lost mothers. *ProPublica*. July 17, 2017. <https://www.propublica.org/article/lost-mothers-maternal-health-died-childbirth-pregnancy>. Accessed October 20, 2017.
21. Ellison K, Martin N. Nearly dying in childbirth: why preventable complications are growing in the US. NPR. December 22, 2017. <https://www.npr.org/2017/12/22/572298802/nearly-dying-in-childbirth-why-preventable-complications-are-growing-in-u-s>. Access January 23, 2018.
22. Martin N, Montagne R. Black mothers keep dying after giving birth. Sharon Irving's story explains why. NPR. December 7, 2017. <https://www.npr.org/2017/12/07/568948782/black-mothers-keep-dying-after-giving-birth-sharon-irvings-story-explains-why>. Accessed January 23, 2018.
23. Martin N, Montagne R. Focus on infants during childbirth leaves US moms in danger. NPR. May 12, 2017. <https://www.npr.org/2017/05/12/527806002/focus-on-infants-during-childbirth-leaves-u-s-moms-in-danger>. Accessed January 23, 2018.
24. Armstrong D. The invention of infant mortality. *Sociol Health Illn*. 1986;8(3):211-232.
25. Kempe CH, Silverman FN, Steele BF, Droegemueller W, Silver HK. The battered-child syndrome. *JAMA*. 1962;181:17-24.
26. Krieger N. Does racism harm health? Did child abuse exist before 1962? On explicit questions, critical science, and current controversies: an ecosocial perspective. *Am J Public Health*. 2003;93(2):194-199.
27. Gravlee CC. How race becomes biology: embodiment of social inequality. *Am J Phys Anthropol*. 2009;139(1):47-57.
28. Adams V, Craig SR, Samen A. Alternative accounting in maternal and infant global health. *Glob Public Health*. 2015;11(3):276-294.

**Claire Wendland, MD, PhD**, is a professor in the departments of anthropology and obstetrics and gynecology at the University of Wisconsin-Madison. Previously, she worked as an obstetrician-gynecologist on the Navajo reservation before returning to graduate school for a PhD in cultural anthropology. Her current research explores explanations for maternal death in Malawi, a context in which mortality rates are very high while the uncertainties surrounding any given death are substantial.

**Related in the *AMA Journal of Ethics***

[How Should Trainees Respond in Situations of Obstetric Violence?](#), March 2018

[Natural Childbirth—a Global Perspective](#), October 2014

[Jumping to Premature Conclusions](#), October 2008  
[Why US Health Care Should Think Globally](#), July 2016

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2018 American Medical Association. All rights reserved.  
ISSN 2376-6980**