Abstract and Keywords

Advancing fair access to evidence-based pregnancy-related services is a critical public health priority. It is widely recognized that there are inequalities in lifesaving interventions. This chapter however addresses issues raised by services whose value or utility are contested. Using illustrative examples of prenatal genetic testing and modes of childbirth, the chapter highlights the ways in which issues of access are complicated by social and cultural ideas about what is valued; discusses contested questions about what is ethically responsible or required of patients, providers, and public health systems in these reproductive health contexts; and addresses areas of needed research and further ethical analysis. It concludes that issues of access in pregnancy-related care must attend both to broad issues of justice and access and to particular ways that pregnancy services are valued, debated, and made available to women who might—or might not—benefit from them.

Keywords: pregnancy, childbirth, justice, prenatal genetic testing, reproductive health, public health ethics

Introduction

ACCESS to pregnancy-related services raises several important issues for public health ethics. Most obvious are inequalities in access to services that are critical to important health outcomes for the pregnant woman and her child. Access to focused antenatal care saves lives, as newborns are 40–50 percent more likely to die in the first month of life if mothers have not received antenatal care (Vintzileos et al., 2002). Access to skilled birth attendants and other evidence-based interventions, such as magnesium sulfate for eclampsia prevention, are associated with reduced rates of maternal mortality (Nour, 2008). Yet there are enormous disparities between and within countries in access to such interventions, raising issues of justice. For instance, Millennium Development Goal 5 for 2015 was universal access to antenatal care, yet the global average of women accessing the World Health Organization’s (WHO’s) recommended minimum of four antenatal care visits is only around 60 percent (UNICEF, 2018; WHO, 2016). Even within high-income
countries, disparities in outcomes, including maternal mortality, are significant and problematic (APHA, 2011). A critical issue for public health ethics is addressing the often complex sources of these inequalities, and working toward universal access to the key health care services that reduce maternal and neonatal mortality and morbidity.

But there is another layer to public health ethics and pregnancy-related services that is less well explored. Much of pregnancy-related care is about provision of services and care whose value or utility is not primarily or exhaustively about direct medical benefit. These include access to termination for women who do not want to become mothers; access to assistance in achieving a biologically related child; and access to meaningful choice and control in how a woman will give birth, care for her newborn, and integrate parenting, work, and future reproductive planning. These are services that merit highly personal decisions, and that intersect with individual and societal values in ways that can be hidden, contested, and varied.

For instance, when describing barriers to access to pregnancy-related services, implicit value judgments about whose reproduction is valued can inform and tacitly shape analyses regarding fertility, and whether to assist or control it. Social scientists have coined the term “stratified reproduction” to characterize differences in how fertility, reproduction, and maternity in some groups are valued and ascribed meaning compared to other groups (Harris and Wolfe, 2014). Stratified reproduction is emblematized by the shameful history in the United States of eugenic sterilization programs that targeted immigrants as well as individuals who were working class, poor, mentally disabled, or racial minorities. But stratified reproduction continues to operate today, albeit in more nuanced ways. It manifests as implicit biases about whose reproduction is valued (and how), which in turn shape access to a range of reproductive and pregnancy-related services.

More familiar are ways in which certain pregnancy-related services run into profoundly contested values. Access to abortion is the obvious example. Much discussion has addressed whether and under what conditions abortion services should be made available, as well as what individuals or institutions should pay for or provide them (Stulberg, Jackson, and Freedman, 2016). More subtle, though, if only because they shadow public health discussions even for those generally supportive of abortion access, are discussions of selective abortion for disability or sex, and how public health decisions about access should frame the values at stake.

Further, even when values are not publicly contested in the way they are for abortion, many important pregnancy-related services involve value-based decisions, where women’s individual values are known to differ, raising complex questions about how public health programs should intersect with individuals’ important personal priorities. Many decisions around pregnancy are less like decisions about setting broken bones (i.e., clear directives based on medical utility calculations), and more like decisions around end of life care (i.e., deeply laden with personal values, bodily integrity, and issues of existential meaning), with a wide range of reasonable decisions that ideally are not only tolerated but supported with information, contextualized counseling, sympathetic alliance, and ac-
access to required care consistent with individuals’ value- and evidence-informed choices. Yet this ideal masks the challenges and ethical trade-offs that are inherent in such contexts. Accommodating choice itself comes with costs, including social resources. And biases about the “correct” or “most reasonable” choice can affect institutional structures in often hidden ways.

In this chapter we highlight issues in this deeper layer of public health ethics around pregnancy-related services by exploring illustrative examples from two areas of maternity care: access to prenatal testing, and access to preferred modes of birth. In each case we highlight the ways in which issues of access are complicated by social and cultural ideas about what is valued; discuss contested questions about what is ethically responsible or required of patients, providers, and public health systems in these reproductive health contexts; and address areas of needed research and further ethical analysis.

**Pregnancy: Access to Prenatal Testing**

Antenatal care is a prime example of a service whose remit has been expanding in ways that magnify several underlying ethical complexities inherent to health care. Prenatal genetic testing is a paradigm case. Driven by a range of factors—including a focus on genetics and health, advancing technologies that predict illness with less expense and less intervention, and financial incentives—prenatal testing has become an expected part of many antenatal care programs. Certainly this is true in high-income countries (HICs). For example, the American College of Obstetricians and Gynecologists (ACOG, 2016) now recommends that all pregnant women, regardless of age, “be offered the option of aneuploidy screening or diagnostic testing for fetal genetic disorders.” Prenatal genetic testing has also been increasingly deployed in low- and middle-income countries (LMICs), notably reflected in the 2010 resolution on the prevention and care of birth defects by the World Health Assembly and the 2011 WHO publication of the first global report on community genetic services in LMICs (WHO, 2012). With the advent of new tests for cell-free fetal DNA in maternal serum, the use of prenatal genetic testing is widely expected to increase, given that these screening tests can be done starting as early as nine weeks of gestation, do not require particular technical skill or instrumentation, do not present immediate risk for the woman or fetus, and can indicate certain genetic abnormalities with high sensitivity and specificity at low cost.

Yet the public health community and relevant governing bodies have struggled with how to think about the role of prenatal genetic testing in health agendas. Certainly, in LMICs, challenging questions persist about how these services compare with foundational antenatal care as ethical priorities for scarce resources. More broadly, though, there are ethical challenges that exist across economic contexts.

For instance, there are deep value-based tensions about how to appropriately frame the social value of prenatal genetic testing. When prenatal genetic testing is offered, it is often done under the rubric of a “preventive” service. Yet, as the disability rights communi-
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Acuity has made vivid, this characterization is problematic (Parens and Asch, 2003). While most preventive services are aimed at preventing a disease (e.g., blood pressure screening to prevent a woman from developing pre-eclampsia), prenatal testing is aimed—primarily at least—at preventing a birth of an affected child. Down syndrome, for example, can only be prevented by preventing birth, though some of its attendant morbidities, such as heart defects, can be treated and their effects mitigated. Indeed, some have offered that there may be health-related benefits to prenatal diagnosis, such as planning for risk-appropriate delivery location and, in rare contexts, therapeutic intervention before birth. Treatment prospects notwithstanding, for the most part, prevention in the context of prenatal genetic testing is achieved through abortion of the entity that would experience disease, rather than preventing a disease harm to an extant person; abortion rates after Down syndrome diagnosis range from approximately 67 percent in the United States to nearly 100 percent in Iceland (Natoli et al., 2012). Such testing cannot be justified by the usual case for advancing the health status of the person who would have disease.

Further, prenatal genetic testing raises vexing ethical questions about the proper role of public health in selective abortion. Clearly, there are general disagreements about the morality of abortion. But terminations based on characteristics of the fetus, including sex and congenital abnormalities, can raise distinct concerns even among those who view abortion in other contexts as morally permissible. If used for sex selection, there are concerns that prenatal testing may reinforce the gendered norms it might be expected to redress. Also, the disability community has raised serious concerns about abortion based on congenital abnormality. What is perceived as a disability stems from a lack of experience with or understanding of a condition; notions of disability are often determined by social institutions and structures that privilege the interests of those with certain intellectual or physical abilities over others; and difference is often turned into disadvantage rather than appreciated as intrinsic to the condition itself. Furthermore, the value of the information gained from prenatal testing varies by context. For example, it is only when women have access to care at high-quality medical centers that prenatal testing may have a role in diagnosing a fetal condition that is possible to repair; conversely, the value of prenatal testing (particularly when it uses limited public health resources) is less certain in contexts where neither medically advanced services nor termination are accessible. These are not just debates over how to set priorities; they interrogate how to understand what values and whose interests are at issue in ensuring access to selective abortion. And the nature and role of these values and interests is contested.

There is yet another layer here. Many believe that, as important as the cultural criticism of selective abortion is, at the end of the day women should have the ability to make choices about their reproductive life, including such private and personal matters as whether to test for or give birth to a child with a disability, and whether or not they are financially or emotionally able to care for a child with disabilities. Reproductive choice as such emerges as a second-order and critical goal for all women, not just those with financial and other resources. Even here, though, there is a distinct group of ethical chal-
First are the challenges that arise out of the important but often blurred distinction between offering and recommending a test or intervention in the context of elective and value-laden care—and that manifest in how the day-to-day exchanges between health care providers and patients relate to public health guidelines (Little et al., 2008). For instance, in the state of California, all medical care providers since 1986 have been required to inform patients in their second trimester of pregnancy about the Prenatal Screening Program, a statewide service that provides optional prenatal screening and follow-up diagnostic testing to all women in the state (California Department of Health, 2018). Notice that the requirement is that patients be informed of the optional program—not that they actually undergo screening or testing.

But as several studies have demonstrated, with the routinization of testing, the message has shifted, and access to informed decision-making has been constrained (Press and Browner, 1994). First, routinization can lead patients to believe that a test offered in the context of pregnancy—particularly one with no immediate medical risks and which can provide information about the health of the fetus—is recommended (Little et al., 2008). Second, it can obscure the merits and even the possibility of not undergoing testing: patients may not be informed about or appreciate the emotional stress and morally complicated choices that testing can engender (Suter, 2002). Indeed, as testing of the fetal genome has expanded to include such technologies as genomic microarray, genomic variations of uncertain significance can be experienced as “toxic”—creating anxiety both among women who carry their pregnancy to term and those who end it (Bernhardt et al., 2013). And third, women who decline testing—particularly those at elevated risk because of age or other factors—may face repeated pressure to undergo testing despite their informed choice (Rapp, 1994; Press and Browner, 1997).

No doubt, practitioners and institutions in some clinical settings have held fast to the importance of patient-centered decision-making and have worked to ensure meaningful informed consent for their patients, including clearing space for decisions to decline screening or forego invasive testing in the context of elevated risk, or referrals to genetic counselors. Even here, there is a further set of challenges, ensconced in guidelines and manifested in the way that results are reported and options are framed—indeed in the very notion of “elevated risk.” For instance, the threshold of risk at which a test is deemed “abnormal” is based on presumptions that do not reflect the range of values that women bring to the prenatal testing context (Kuppermann et al., 2004). As Kuppermann and others have argued, in the United States this threshold has been linked to the risk of having an affected fetus for a healthy thirty-five-year-old woman (Kuppermann et al., 2000). It turns out that this risk is roughly equal to the risk that was associated with procedure-related miscarriage among women undergoing invasive testing. But, of course, individual women vastly differ in their views of the two outcomes. There is no recoverable generalized trade-off between the outcomes—reflecting again challenges to ensuring in-
formed decisions about, and meaningful access to, this important if contested pregnancy-related service.

**Birth: Access to Maternity Care Options**

As the prenatal testing context makes clear, how public health interventions should ensure access in the context of pregnancy is a value-laden issue. Maternity care also reflects this extra layer of complexity. Should the focus be put on improving delivery care in medical institutions or improving resources for deliveries occurring in the range of settings, including freestanding birth centers and homes? Safety remains a top priority of public health interventions around birth, but disagreement around quality measures complicates how delivery of care is evaluated by standards of established public health ethics frameworks. Further, once a threshold of safety can be established, other aspects of giving birth that matter deeply to women come to the fore, raising questions about how they should inform public health approaches to maternity care.

The process of shaping interventions to ensure safety often gets entangled in disputes about what is a “normal” or a “good” birth. It is pertinent here to consider varying definitions of a “normal” or “good” birth, and to question who has access to them. Conceptions of what comprises a “good birth” vary, both on a cultural level and on an individual level. Central to reproductive justice is the ability of individuals to make their own choices about reproduction, including decisions about whether, when, and under what conditions they would like to give birth. A focus on patient preference and access to services is crucial and goes hand in hand with examining differing standards to measure the quality of maternity care.

From the standpoint of medical obstetrics, the “success” of a birth is usually measured in terms of discrete health outcomes (e.g., rates of prematurity, Apgar scores, hemorrhage, NICU [neonatal intensive care unit] transfer, maternal or neonatal mortality). In contrast, within the midwifery literature, the “success” of a birth is often measured by its physiologic “normalcy” which usually tracks with avoidance of medical intervention (e.g., birth without anesthesia or instrumentation). Yet neither of these approaches fully captures the priorities of those giving birth (Lyerly, 2013). Those who may need medical intervention—say a person for whom labor is unsafe because of previous uterine surgery—will not have access to a “good” birth according to the midwifery model standards, due to a medical indication for a cesarean section. On the flip side, a woman who experiences a difficult or traumatic birth (especially in a hospital setting), but from which she and her baby emerge physically healthy, may find her story of difficulty to be discounted due to the view in obstetrics that good medical outcomes should be “enough.” Described as the “birth wars,” these polarizing frameworks often leave women stuck between opposing narratives of what comprises a “good” birth—and without a narrative that captures what it is that they themselves value in the birthing process (Lyerly, 2013).
This conflict is further reflected in the ways that biomedical and global health policy interventions are working toward shaping the developing maternity care systems of LMIC countries. Take, for example, conditional cash transfer programs that incentivize women to give birth in medical institutions. Many countries have implemented such programs, which conceptually equate “safer delivery” with “institutional delivery” (Lim et al., 2010; Barrett et al., 2016). However, a major critique of these initiatives is that parallel efforts have not been made to ensure that the respective health care systems have the facilities or capacities to accommodate or ensure quality care for increased institutional births. Nepal’s Safe Delivery Inventive Program and India’s Janani Suraksha Yojana initiatives failed to significantly decrease neonatal mortality and maternal mortality (respectively) among women who received incentives and gave birth in institutions or with a skilled attendant present (Lim et al., 2010; Gaarder, Glassman, and Todd, 2010).

Evaluations of a program in Cambodia made vivid the reasons that many women did not deliver in hospitals even with a voucher incentive, including transportation constraints, an inability to leave home given child-care responsibilities, and poor staff attitudes at health centers (Ir et al., 2010). All participants pointed to a strong preference for home delivery. Indeed, the authors note that many who did participate in the program already had access to skilled birth attendants at home, raising the question of whether the program served those most in need. Improving safety of delivery is therefore likely to depend not simply on clearing a path to birth in medical centers, but also on ensuring home births are attended by skilled health care providers. Not only does the preference for facility-based birth fail to attend to the priorities and desires of childbearing women, but it also often fails to achieve optimal health outcomes for those most at risk for harm.

There is also a way in which increased accessibility of interventions can set back maternal and infant health interests. For example, increasing rates of cesareans demonstrate how overuse of technology can occur as an unintended consequence of a confluence of policy, technology, and shifting cultural norms. The WHO estimates that approximately 15 percent of cesarean sections are medically necessary (WHO, 2015). When countries have rates significantly lower than that, there is cause to worry that women are not receiving medically necessary care. Yet the opposite concern has also emerged, particularly in HIC countries like the United States, where the cesarean rate rose 60 percent between 1996 and 2009, and now is around 32 percent (Martin et al. 2018). Cesareans, like any operation, carry risks, such as infection, hemorrhage, and complications of anesthesia. Additionally, a prior cesarean creates increased risks for future deliveries, whether vaginal or cesarean (WHO, 2015). Higher than medically necessary rates of cesareans mean childbearing women will face higher levels of risk, and for non-medical reasons. Elevated rates of cesarean in the United States reflect several such non-medical factors, among them liability concerns, constraints on patient choice, hospital policy, and cultural valuation of a medicalized birth. Efforts to remedy inequalities in access to medical care do not always address such complex questions around when and under what circumstances a procedure is beneficial. When a medical center-based birth or a cesarean is explicitly or structurally
incentivized in an implementation program or public health system, the question of how to ensure appropriate access to maternity care is ethically complex.

These examples illustrate that when prenatal care focuses on a narrow or unexamined set of services, and when resources are focused on improving access to those specific services, many women are either left behind entirely or experience care shaped by values they do not share, resulting in inequalities endemic to and often perpetuated by the current public health infrastructure. Institutional structures, including procedural and administrative issues such as staffing patterns, can put pressure on women’s meaningful access to certain types of services, especially for those whose idea of valued care, while reasonable, does not match those of an aggregated mean or majority (Obstetrics and Gynecology Risk Research Group et al., 2009).

The rate of cesarean sections in the United States also serves as an example of stratified access to delivery services. Women on Medicaid—a public health insurance program in the United States—were more likely to report an inability to plan a vaginal birth after cesarean than women with private insurance, and also more likely to report provider unwillingness to accommodate vaginal birth after cesarean (VBAC) requests (Childbirth Connection, 2013). Thus, how a birth occurs is all too often related not to patient “choice” but to identity and correlative social determinants of health. Between 2008 and 2010, Medicaid funded 48 percent of births in the United States, as well as the greatest number of births in the American South, where there are higher numbers of black and Hispanic people enrolled in Medicaid (Kaiser Family Foundation, 2015; Markus et al., 2013). Among births supported by Medicaid, people of color were more likely to feel as though they did not have a choice in their birthing attendant/obstetrics provider, and were more likely to “report poor treatment” in hospitals (Childbirth Connection, 2013). Doula services—preferred by many and associated with shorter labors and lower rates of cesarean and instrumental births—are not covered by Medicaid.

Thus, access to appropriate maternity care is stratified in a way that is reinforced by the current system. While the global maternal mortality rate is declining, the rate in the United States is rising and is significantly higher than in other HICs. Despite significant investment in the US health care system and the fact that the public cost of maternal and newborn care is much higher than in other developed countries, the majority of maternal deaths in the United States are preventable (Agrawal, 2015). In addition, maternal mortality is correlated to race, ethnicity, and socioeconomic status in the United States—in 2005 the rate of maternal mortality for black women was almost four times the rates for Hispanic and white women (Kung et al., 2008; APHA, 2011).

For some, meaningful access to delivery care includes hospital care and medical intervention, while for others it is the ability to choose a delivery option that minimizes medical intervention and is more cost-effective, such as a delivery at a birthing center or a home birth. For some, it means access to anesthesia during labor (e.g., an epidural), while for others it is having their decision to refuse an epidural respected. Meaningful and equal access on an individual level means that all people who are giving birth be advised and in-
formed respectfully and neutrally about the risks and benefits of all options, and be given a choice in the setting, manner, and companionship for delivery. “Respectful maternity care” advocates work both nationally and globally to improve access to and quality of maternity care. But there is complexity even here. Some advocate for a strong shift toward evidence-based practice, while others give attention to nuance, noting that what counts as evidence can be shaped by priorities of the research community and cultural understandings, as well as by challenges to understanding, interpreting, and applying clinically the assessments of risk in the context of pregnancy (De Vries and Lemmens, 2006; Lyerly et al., 2009).

Conclusion

Issues of access in pregnancy-related care must attend to broad issues of justice and access, as well as to the often very particular ways that pregnancy services are valued, debated, and made available to women who might—or might not—benefit from them. Maternity care is in many ways an issue at the crux of public health and ethics, as it is the literal first step in improving health outcomes for individuals in the global community. It is also an arena that intersects with deeply personal, varied, and sometimes contested values. Those charged with developing, evaluating, and deploying pregnancy-related services for the public health sphere need to be mindful of several critical issues: values vary among women—and can change over the course of a given woman’s life; vigilance is required to limit the harms from biases of stratified reproduction, in which some women’s reproduction is valued but that of others is not; and pregnancy-related care must be mindfully shaped around the lives of the women who need it in order to remain ethically relevant.

References


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Notes:

(1.) Although we use the term *women* throughout this chapter, we recognize that not all individuals with female reproductive systems identify as women. The ethical complexities we discuss are meant to be inclusive of the intersectionality of individuals who do not identify as women but can become pregnant and give birth.

(2.) Used here, the term *prenatal genetic testing* includes screening tests that use serologic tests, maternal age and history, and sometimes ultrasound to offer a likelihood of fetal aneuploidy; and also invasive diagnostic testing that can definitively diagnose a genetic disorder by testing amniotic fluid or chorionic villous tissue.

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