Redefining Safety: A Reproductive Justice Ethics of Care Approach to Maternal Health

Elizabeth Balskus

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REDEFINING SAFETY: A REPRODUCTIVE JUSTICE ETHICS OF CARE APPROACH TO
MATERNAL HEALTH

A Dissertation
Submitted to McAnulty College and Graduate School of Liberal Arts

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By
Elizabeth Balskus

December 2022
REDEFINING SAFETY: A REPRODUCTIVE JUSTICE ETHICS OF CARE APPROACH TO MATERNAL HEALTH

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ABSTRACT

REDEFINING SAFETY: A REPRODUCTIVE JUSTICE ETHICS OF CARE APPROACH TO MATERNAL HEALTH

By

Elizabeth Balskus

December 2022

Dissertation supervised by Joris Gielen, PhD

This dissertation argues for the adoption of a multi-dimensional concept of safety in healthcare to include emotional, psychological and communal health. It then illustrates how this concept of safety is foundational to a dignity-enhancing ethics of care approach that finds its normative grounding in Reproductive Justice and human capabilities, given that both patient and provider need to feel safe in order to fully engage in a dialogical-interpretive process of care and that caring efforts must strive to be equitable on both interpersonal and structural levels. This framework is then applied to maternal health, showing how an approach to care with a multi-dimensional concept of safety as its foundation opens up the space to truly care for mothers and infants in ways that help them flourish. This flourishing should be the goal of maternal care.
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Chapter One: Introduction

*Not everything that is faced can be changed, but nothing can be changed until it is faced*

- James Baldwin

This dissertation will argue for the adoption of a multi-dimensional concept of safety in healthcare to include emotional, psychological and communal health. It will then illustrate how this concept of safety is foundational to a dignity-enhancing ethics of care approach that finds its normative grounding in a reproductive justice and capabilities framework, given that both patient and provider need to feel safe in order to fully engage in a dialogical-interpretive process of care and that care does not qualify as good care if it is not also just. This framework will then be applied to maternal health, showing how an approach to care with a multi-dimensional concept of safety as its foundation opens up the space to truly care for mothers and infants in ways that help them flourish. This flourishing should be the goal of maternal care.

After introducing the topic of safety in healthcare and providing a roadmap for the dissertation in an introductory chapter, Chapter 2 will begin with an overview of how safety in healthcare has traditionally been understood within the United States, showing how traditional concepts of safety focus almost exclusively on patient safety and largely define safety as merely the absence of physical harm. This chapter will then offer an argument for a redefinition of safety to include emotional, psychological, and communal safety. To do so, it will draw upon Bessel van der Kolk’s conception of safety as a state, established and maintained through reciprocal relationship, in which individuals are “truly heard and seen” and in which there is a feeling of being held by someone’s “mind and heart”.
Given that safety is established through relationship, an ethics of care approach is adopted as an ethical framework through which to understand safety and the role that safety plays in providing good, quality care. Ethics of care presents an ethical framework that challenges the primacy of “pure reason”, the autonomous individual, and the rejection of emotions in ethical decision making in favor of a framework that arises out of and through lived relationships and positions caring relationships as a model for when ethical action takes place and how ethical, caring practices can be nurtured and promoted.

However, in order to offer a tenable alternative to traditional Western philosophical ethical theories, an ethics of care must also be able to provide normative standards for ethical action that promote justice and flourishing for all humans, not just those for whom an individual might be inclined to care for due to shared interests, familial bonds, etc. For this reason, a Reproductive Justice approach in dialogue with a Capabilities Approach to normativity, which highlights the centrality of human dignity as well as commonly shared capabilities that humans possess and should support each other in cultivating while explicitly exploring the relationship between individual rights and community rights, can provide a foundation through which to gauge what constitutes good, dignity-enhancing care.

Given the importance of feeling safe to this ethics of care approach, the question “What Does It Mean to Feel Safe?” will then be explored, drawing from insights in Trauma Studies and Feminist Phenomenology in order to glean how safe and unsafe relationships feel in a healthcare context and what can be learned from these experiences. This chapter will then illustrate how Narrative medicine provides a means through which providers can understand the worldview and perspectives of their patients so that they can care for them as human beings and not only corporeal bodies, as well as establish a partnership, a collaboration between patient and provider
in which they work together in order to achieve their shared aim of accomplishing what is best for the patient. The first section of this chapter concludes by integrating the previous components of the chapter into a concept of safety as it operates within a dignity-enhancing approach to care. Within this framework, safety holds a central and foundational role. Both patient and provider need to feel safe in order to fully engage in a dialogical-interpretive process of care. In order to achieve safety in these relationships, hospitals need to understand and support the broader social contexts in which providers and patients exist.

The second half of this chapter will then explore the origins of how patient safety has traditionally been considered specifically within psychiatric care. By illustrating how current components of psychiatric care still bear the conceptual markings of the age of institutionalization, we can better understand how contemporary understanding of safety in psychiatric care now centers around the notion of patient risk. This has led to environments in which patients themselves are considered a risk to be maintained and controlled. The impact of this is explored within the inpatient setting, the Emergency Department, and outpatient behavioral health treatment. We will then explore the ways in which a Public Health framing of safety, in combination with an emphasis on surveillance, have contributed to, and perpetuate the risk management model of safety, particularly in behavioral health and in considerations of individuals with Substance Use Disorders. This chapter will conclude by illustrating the impact that behavioral health policies have on healthcare institutional policies as well as the way in which our conceptualization of behavioral health treatment influences the way in which all patients are treated in healthcare settings.

Chapters Three through Six explore the application of the ethical framework laid out in Chapter 2 to maternal health. They are structured to reflect the four ethical elements of caring
posed by Joan Tronto: Attentiveness, Responsibility, Competence, and Responsiveness. These four ethical elements correspond with four phases of caring: recognizing that there is a need for care and caring about that need, realizing that one has a responsibility to care for another once the need has been recognized as such, providing care for the individual that is competent and appropriate, and evidence that the care has been effective and that the care received has met the need it sought to address. By structuring these chapters in this way, we can explore the four ethical elements of caring and their more general relationship to safety while also understanding how they are expressed in specific contexts within maternal health.

Chapter Three will illustrate the significance of moral attentiveness in both safety and in a dignity-enhancing care ethics approach to maternal health. The first half of this chapter begins with an analysis of the significance of moral attentiveness within an Ethics of Care and an exploration of the ways in which imbalances of social power and privilege across gender, race and language encourage and shape the inattentiveness of nursing staff when caring for patients belonging to an oppressed social group. It will then explore the ways in which moral inattentiveness perpetuates the alarmingly high racial disparity in maternal mortality in the United States by placing the work of care ethicists in dialogue with the research of prominent voices in the Reproductive Justice movement. This moral inattentiveness will be considered within the three time periods considered in the CDC’s report detailing the findings of 9 US Maternal Mortality Review Committees: during pregnancy, day of delivery, and postpartum. We will then consider the role of moral inattentiveness in the death of Kira Johnson, illuminating through narrative one way in which a lack of attentiveness on the part of hospital staff to the vulnerability of their patient can perpetuate the violence of structural racism through individual
provider-patient relationships. This section will conclude with a consideration of the role of obstetric racism in perpetuating disparities in severe maternal morbidity.

The second half of this chapter will explore what a robust notion of moral attentiveness might entail. It will do so first by returning to the Reproductive Justice Capabilities Approach discussed in Chapter 2, then exploring the role of self-understanding in building just, moral relationships and the necessity of cultivating attentive communities of healthcare providers in order to promote a more complete and caring professional culture. We will then turn to Annelies van Heijst’s conception of healthcare work that conceives of itself as a practice of presence, showing how the work of healthcare professionals is a vocation in which one seeks to become an ongoing presence in the life of the patient in a way that is attentive to the needs of the patient and is determined by the patient. This necessitates the collaboration and co-creation of patients in their own care.

This chapter will conclude by giving an account of moral attentiveness in the postpartum period and illustrating the necessity of community partnerships in providing morally attentive care, as well as the role health plans can play in empowering community partnerships by including the work of community-based organizations in their perinatal reimbursement models and adequately funding the essential health care that community-based organizations provide.

Chapter 4 will illustrate the responsibilities that healthcare organizations have in supporting safety, with a focus on maternal health, and will explore the potential of Perinatal Quality Collaboratives to provide a structure for implementing statewide networks of care as well as the limitations of the current PQC model. It will argue that the current widespread mistreatment of women during childbirth in the United States, and in particular, the mistreatment
of women of color by their care teams constitutes a failure in responsibility, and will explore the question of who is responsible for this mistreatment, as well as the role that provider secondary trauma plays in inflicting harm upon patients and providers alike, and the responsibility that healthcare organizations have to respond to the secondary trauma of their employees. This section will then conclude by considering the work of the Alliance for Innovation in Maternal Health and the role of Patient Safety Bundles in building hospital infrastructure for responsibility, as well as the limitations of this approach if does not include robust attempts to promote empathy and caring at a basic, human level and efforts to help hospitals understand their role and responsibilities to the communities of which they are a part.

The second half of this chapter will explore the ways in which Perinatal Quality Collaborative (PQCs) offer a structure for collaboration on a statewide level to improve health outcomes for specific populations, with a particular focus on statewide Opioid Use Disorder initiatives. After explaining ways in which the PQC model has been adopted as a strategy to improve the identification and care for families impacted by Opioid Use Disorder on the state level, we will then explore the greatest opportunities for improvement in the structure of PQCs, showing how these initiatives offer promising solutions but cannot remain hospital-centric if they are to truly be networks of care. This chapter will conclude by illustrating how a reproductive justice approach to the Perinatal Quality Collaborative model can address some of the limitations of the current PQC model, transform current notions of collaboration, and provide a framework for expanding current networks of care.

Chapter 5 will address the need for insurance reimbursement models that reflect a patient-centered approach to care, as well as the need to measure quality of care in a way that reflects what matters most to patients. It will illustrate how healthcare payment models can play
a role in supporting competence in healthcare and will argue for the adoption of value-based bundled payment models in maternal care. It will then illustrate the importance of ensuring the pregnancy episode includes a full year’s coverage postpartum to ensure that women do not lose their insurance coverage in the immediate aftermath of childbirth. We will then emphasize the necessity for collaboration with a variety of stakeholders when designing bundled payment models to ensure that the voice of patients and families are heard and centered in the process and community-based services are being considered and reimbursed for during the peripartum period.

The second half of this chapter focuses on the question of how to measure quality in maternal health and explores the history of quality measurement in the maternal health space, then turns to the role of safety in quality measurement. While more traditional models of measuring quality focus on process measures, or measures that providers value/feel responsible for, we need to move towards implementing quality measures that center what is important to patients and measure not just whether or not mother and baby survived, but the longer term health outcomes of the mother-infant dyad. We will then examine the need for equity to be centered in quality measurement and quality improvement efforts. In order to address issues of inequity, we first need to accurately measure the inequities that currently exist, as well as our responses to those inequities. Organizations should engage in a dialogical-interpretive process in order to understand the cause of any disparate treatment and the effect that this treatment has had on their patients. In this way, data collection and quality improvement efforts can be integrated into the caring process itself, and can provide another means through which providers, patients and organizations can work together to provide better care and more equitable care.
Chapter Six will focus on the question of responsiveness in providing good, quality care in maternal health. It will explore the role of responsiveness in an ethics of care as well as the role of safety in contemporary conceptions of responsiveness in peripartum health. It will then illustrate how the ways in which maternal substance use disorder has been conceptualized and treated have neglected the role of vulnerability and Adverse Childhood Experiences (ACEs) in a way that demonize pregnant and postpartum women with substance use disorders and misconstrue and negatively impact their maternal subjectivity and will explore the ways in which infant safety has historically been weaponized in the response to maternal substance use on racist and discriminatory grounds. It will then consider Plans of Safe Care as an approach for promoting health for the substance-exposed mother-baby dyad, arguing that a collaborative, wrap-around support system for families is needed, but must be divorced from criminal and legal systems.

The second half of this chapter examines the current state of the maternal health workforce in the United States within its historical context in order to understand the role of racism in shaping the lack of racial and ethnic diversity in the contemporary American maternal health workforce. It will then explore how increasing diversity in the maternal healthcare workforce can promote the safety of mothers and infants, decrease racial inequities in maternal health outcomes, and further the goal of providing dignity-enhancing care. Having examined the role that increasing racial/ethnic diversity can play in providing better, more just maternal care, we will then turn to the role that increasing the use of multi-disciplinary teams can play in providing better, more just maternal care, with special consideration given to the Midwifery Model of care. This chapter will conclude with an examination of Maternal Mortality Review
Committees (MMRCs) and will argue both for the adoption of a Healthy Equity framework for MMRCs as well as for the necessity of including ethicists on MMRCs.

The concluding chapter of this dissertation will tie together the content of the previous six chapters, showing how good care is by necessity also always safe care, and that good, safe care is owed to all. A dignity-enhancing ethics of care approach to healthcare with a multi-dimensional concept of safety as its foundation allows us to truly care for individuals in ways that helps them build rich, meaningful lives. Within this project, this framework is applied specifically to maternal health, but its application highlights the necessity of adopting this approach across a continuum of care. To truly build safer, better, caring relationships, we have to restructure our organizations, communities, care models and reimbursement models to support the flourishing of individuals, families and communities. While we can illustrate the efficacy of this approach when caring for particular patient populations, in order to be truly effective and truly equitable, we should fight for its application across healthcare. The goal of healthcare should not be to only reduce negative health outcomes but to promote human flourishing.
Chapter 2: Towards a Multi-Dimensional Concept of Safety

People are trapped in history and history is trapped in them

- James Baldwin

2a. Redefining Safety: An Ethics of Care Approach

Introduction.

Patient safety is a stated priority of the majority of healthcare organizations. Hospitals, clinics, and community-based organizations delivering care to patients typically have policies, staff education and training, and, often, sections of their mission statement centering the importance of patient safety in providing quality care to those that they serve. However, historical and contemporary approaches to safety have relied upon a conception of safety that almost always only considers patient safety and defines safety as “freedom from accidental injury….from the patient’s perspective” wherein the injury being prevented entails physical injury (i.e. cases in which the treatment a patient received resulted in medical error, bodily harm, or death) and other types of harm, such as psychological or emotional harm, are either excluded altogether or only included as an afterthought.¹ There are notable exceptions to this in the case of trauma studies, which will be discussed in subsequent sections of this chapter.
I. Safety in Healthcare

*If we continue to speak the same language to each other, we will reproduce the same story*

- Luce Irigaray, “When Our Lips Speak Together”

Discussions of safety in healthcare within the United States have taken a particular shape due to their origins. Therefore, in order to understand both what our contemporary concept of safety entails and how it can be expanded, we must first examine the context out of which our current conception of safety arose.

**a. To Err is Human: The History of Safety in Healthcare**

While the Hippocratic mandate to “do no harm” is a foundational component of the Western medical tradition, patient safety did not emerge as a central concern that should be addressed systematically through political, organizational, and economic efforts within the United States until the publication of the Institute of Medicine (IOM) *To Err is Human: Building a safer health system* report in 1999.² The report was the first of its kind and has greatly influenced nearly all subsequent discussions of both patient safety and medical error in the United States.³ The report detailed the shockingly high rates of medical error occurring across the nation, revealing that more people die annually as a result of medical error than as a result of motor vehicle accidents, breast cancer, or HIV/AIDS, and argued for immediate policy changes to begin addressing preventable medical error.⁴

Notably, the report emphasizes that to adequately address the question of medical error, we must cease looking at safety and medical error as the failings of individual “bad doctors” but
as the consequence of “not having organized systems of care with clear lines of accountability.”

Weaving safety into processes of care themselves is the only way to ensure that the safest means of providing care is also the easiest means of providing care: a characteristic which is essential to improving care particularly in the context of emergency departments, ICUs, and other spaces in which the care being provided is often emergent, fast-paced, and complex. The report also underscores the foundational relationship that safety has to quality of care, stating explicitly that, “although safety does not guarantee quality, it is a necessary prerequisite for the delivery of high-quality care [emphasis added].”

The publication of the IOM report resulted in the Center for Quality Improvement and Patient Safety (CQuIPS) housed by the Agency for Healthcare Research and Quality, as well as various national policies about medical error and reporting systems to track and learn from medical errors. Moreover, one can argue that the call to action of To Err is Human sparked nationwide efforts in quality improvement and risk management within hospitals in particular. While discussions of quality of care in healthcare literature are currently much more frequent than discussions of patient safety, safety’s essential relationship to quality means that even when safety is not explicitly being discussed as the focal point of quality care debates, it is still an important factor when considering any quality measure.

While the importance of the IOM report’s contents for igniting nationwide efforts to improve safety in healthcare cannot be understated, it is also important to note what To Err Is Human does not contain in its analysis. The report’s authors themselves explain that there are three components that arose in the committee’s conversations about patient safety that were not included in their report but are, nevertheless considered relevant: 1) the values and attitudes of healthcare providers and organizations; 2) the safety of healthcare workers (although it is noted
that the authors believe that steps to improve patient safety will also most likely improve employee safety as well); and 3) access to care, wherein access is defined by a patient’s ability to obtain any care at all.\(^8\)

**b. Safety Today**

While the publication of *To Err is Human* was essential in sparking a substantive conversation about patient safety in healthcare on a national level, the report’s approach to the question of safety as merely a matter of harm prevention and its omissions of considerations of the values and attitudes of providers/organizations, the safety of workers, and a more robust consideration of how access to care (or lack thereof) effects safety and quality of care have had major consequences in how conversations regarding safety in healthcare have unfolded in the 22 years since its publication. Even contemporary efforts to understand and communicate about safety in healthcare that attempt to incorporate the voices of patients and providers, such as the FrameWorks Research Institute’s *Safety is More than Caring* report, draw upon *To Err is Human* in two very telling ways. First, the only safety seriously considered is the safety of patients. Second, safety is thought to be comprised by “errors of commission and omission.”\(^9\) Within this framework, safety is defined by the absence of harm, or, to use the language of both reports, the absence of errors.

Errors of *commission* – instances such as medication errors or “botched” surgeries, where providers actively make a mistake that harms the patient – and errors of *omission* – instances where providers fail to follow up on test results or do not act with haste when a patient reports symptoms that should prompt action from the care team and therefore passively harm their patient through ignorance or inaction – are still the most commonly used categories when
discussing patient safety and the prevention of harm.\textsuperscript{10} The assertion of safety as the absence of harm results in a definition of safety that is negative in nature: a conception of safety that is not a positive assertion of a state of being, but rather, only the absence of a state of harm. Notably, as more evidence has suggested that “physical” healthcare and behavioral health be integrated (for example, in Patient Centered Medical Homes, where primary care and behavioral health care are housed together and approached holistically) discussions of safety have begun to acknowledge that psychological harm should also be incorporated into considerations of harm done to patients.\textsuperscript{11} However, as is often the case with Patient Centered Medical Homes themselves, the attempt to incorporate behavioral health into physical health is often enacted in a way in which psychological wellbeing is still considered less important than physical health and something that can be incorporated into a physical framework of health without having to substantially and fundamentally change the manner in which health is conceived of and supported.

It is also important to note that, although the publication of \textit{To Err is Human} began an important conversation about patient safety in the United States that did result in policy and organizational shifts, the pervasive devastation of preventable medical error has not substantially decreased in the 22 years since its publication.\textsuperscript{12} A study from Johns Hopkins University in 2016 found that medical error was the third leading cause of death in the United States.\textsuperscript{13} While there have been subsequent articles questioning the conclusions of that particular study, even those critical of the Johns Hopkins study admit that if rates of medical error have decreased since the late 1990s, they have only decreased slightly, but have most likely stayed consistent or increased over time.\textsuperscript{14}

Despite the efforts of hospitals, providers, and patient advocates in the past two decades, medical error still occurs at unacceptably high rates, and our conception of safety entails, not a
positive state to strive towards, but, rather, merely the absence of harm.\textsuperscript{15} In order to adequately address the question of safety and to improve quality of care for patients, we need to take a step back and reevaluate what safety consists of and how the healthcare community and society at large can work towards safer care and safer communities. An Ethics of Care can help guide this reevaluation.

II. Ethics of Care

Safety is a state of being, but it is established, first and foremost, through relationship.\textsuperscript{16} This assertion from Bessel van der Kolk will be explained in further detail as this section unfolds. Because of the fundamentally relational nature of safety, an ethics of care approach can provide an ethical framework through which to both understand the multi-dimensional, relational nature of safety and to build more robust attempts at cultivating and prioritizing safety as an essential component of good, ethical care.

a. Ethics of Care: An Ethics of Relationship

Ethics of Care originated out of the lived experiences of women who found themselves in de facto caring positions both in their interpersonal relationships and their positions within society but found that the caring work in which they were engaged was devalued, excluded from political discourse, and lacked representation in the history of ethics and philosophy.\textsuperscript{17} However, despite its origins in the lived experiences of women and its status as a branch of feminist theory, Ethics of Care provides a framework that can be applied to all people given its foundational claim that the need for care is universal.\textsuperscript{18}
Virginia Held claims that broadly speaking, an Ethics of Care should contain five central features. First, the primary concern of Ethics of Care should be the moral significance of recognizing and responding to the needs of “the particular others for whom we take responsibility.” All human beings need care in order to survive. While this need is most obviously seen in the cases of babies and individuals who do not have the capacity for independent living due to their physical and/or mental status, this need for care occurs throughout all of our lives in times of illness, emotional distress, and other states of vulnerability. Second, an Ethics of Care sees the moral value of emotions rather than positioning “objective reason” as the only relevant determinant for guiding moral theory. Ethically relevant emotions such as sympathy, empathy, and attentiveness should be cultivated due to their influence in promoting moral responsiveness to the needs of others. Third, Ethics of Care does not find its starting point in abstract theory, but rather begins with the actual lived relationships within which one finds oneself. Rather than beginning with universal principles that are then applied to specific circumstances, Ethics of Care begins with lived relationships. Fourth, Ethics of Care seeks to challenge the traditional distinction made in liberal political frameworks between the public and the private. As Tronto points out, within traditional liberal frameworks, the boundary between the personal and the public has been constructed in ways which actively exclude women and individuals engaged in caring practices from having a voice in politics and reinforce power structures on a familial and political level that oppress women and other marginalized groups. Finally, Ethics of Care contains a reconceptualization of the self as a relational, interdependent being. This conception differs from traditional Western philosophical views of the individual as an autonomous, independent moral agent who both makes decisions and acts from a fully autonomous standpoint.
From Held’s five central features, it is clear that Ethics of Care posits an ethical framework that challenges the primacy of “pure reason,” the autonomous individual, and the rejection of emotions in ethical decision making in favor of a framework that positions caring relationships as a model for when ethical action takes place and how ethical, caring practices can be nurtured and promoted. However, the question remains: what is care? While the definition of care can be and is debated, Tronto aptly answers this question by pointing to four central characteristics of care. First, care involves “reaching out to something other than the self.” Second, care necessitates action. If people care about something, they will act in ways that show that they care. Third, caring is a type of cultural practice and the way in which care is performed is informed by and occurs within specific cultural contexts. Fourth, care is ongoing: “both a practice and disposition.” Framing care in this way is advantageous because it shows how morally significant emotions motivate caring actions, it allows us to articulate caring about situations that go beyond those involving only humans (e.g. caring about the environment); it provides a framework for understanding why caring practices look different in different cultures, and it shows that care is often a process that needs to be returned to and re-evaluated over time in order to assess its ongoing appropriateness.

Due to its starting point in lived, concrete relationships, an ethics of care also necessitates an understanding of the social and political positions one inhabits within and through any relationship. Adopting an ethics of care approach, Margaret Urban Walker argues that morality is a “socially embodied medium of mutual understanding and negotiation between people over their responsibility for things open to human care and response.” Morality in Walker’s framework entails individuals in specific, embodied, social relationship who develop practices of responsibility based off of their individual values. Inherent in adopting morally sound practices
of responsibility is the understanding that the context in which one is living shapes both one’s conception of self, but also how others are conceptualized and viewed, resulting in specific responsibilities to care for individuals who are living in contexts in which they are discriminated against, made more vulnerable to the potential of harm, or neglected by other individuals or society at large.33 Morality consists of practices of responsibility in relationship, and these practices and relationships are shaped by the contexts in which moral actors live.34

b. A Reproductive JusticeCapabilities Approach to Normativity in an Ethics of Care

One of the most significant challenges levelled against Ethics of Care is the concern that it is unable to provide normative standards for ethical action. If ethical frameworks exist to help guide our actions, it is imperative that there are standards by which to judge whether or not an individual has acted in a way that is morally good. Therefore, if Ethics of Care is unable to provide standards for evaluating actions, this would be a monumental barrier to adopting Ethics of Care as a theoretical framework. In order to answer the question of normativity within Ethics of Care, we must be able to determine both what constitutes caring and also what constitutes good care.

Care ethicists have posited different answers to these questions. Held approaches the question of normativity from the perspective of answering the question “what does it mean to be a caring person?”35 A moral person, according to Held, is someone who understands that her existence is inherently relational and because of this, she is born with moral responsibilities towards others. If one has this understanding of being a person with moral responsibilities/burdens, then one is capable of answering at least one aspect of ethical normativity: why should I care for others? Individuals should care for others because of the
interdependent nature of existence as a human being. Because we exist within and because of relationships, we have an ethical duty to respond to the needs of those for whom we have an ethical responsibility.36

This approach may provide an answer to the question of why individuals should care for one another but does not answer the question of what constitutes good care and how those engaged in caring practices can evaluate whether or not their attempts at caring have been successful. In response to these concerns, Kittay has suggested that care is an “achievement term”: one can only say that she has cared for another if her actions have successfully resulted in care.37 While this approach does attempt to directly answer the question of what constitutes good care, the relational/subjective nature of Ethics of Care makes concretely grounding Kittay’s approach somewhat difficult. If an individual provides what she believes to be care for another person but the recipient of the care does not find the carer’s actions to be sufficient, can we say that someone has acted in a caring way? For example, if an individual splits the contents of her water bottle in half with her friend on a hot day but her friend is still thirsty and is not satisfied with less than the entirety of the water bottle’s contents, would we say that the individual has not cared for her friend at all by giving her half of her water simply because the friend is not satisfied with the portion of the water she has been given? Without a grounding for the conditions in which one can be said to be cared for, the “success”/appropriateness of caring actions will fall into the dangerous territory of ethical relativism (i.e. he said/she said).

Martha Nussbaum approaches the question of ethical normativity from a human capabilities approach. Nussbaum argues that the political philosophy of the West has historically failed to provide a framework for understanding and promoting justice. She argues that the question of justice should be centered around human capabilities: “what people are actually able
to do and be” that allow individuals to live a life of human dignity. These capabilities are proposed as a foundation for a pluralistic society in which human dignity and basic human capabilities are a shared commonality amongst differences. Within this framework, the success of one’s caring efforts is measured by the extent to which it allows the individual being cared for to flourish. If a society/community/organization does not provide the opportunity for all of its occupants to flourish, it cannot be said to be just.

The central human capabilities that Nussbaum identifies are as follows: “life, bodily health, bodily integrity, senses imagination and thought, emotions, practical reason, affiliation, other species, play, and control over one’s environment.” One should be ensured a life that is not cut short or diminished to the point where it feels unbearable, should be allowed to have health, shelter and enough food, to be safe from assault, and should have autonomy over one’s body. One should be able to use one’s sense and imagination to create and enjoy the world. One should be able to love and care for others, to create one’s own idea of what a good life entails; to live with and care for other humans and animals and be treated with dignity. One should be allowed to play and to participate in politics. Given that human interaction, relationship and community are central to the majority of these capabilities, articulating these capabilities allows us to understand the fundamental, multi-dimensional aspects of what constitutes being a human: a human worth of dignity and respect.

The articulation of these capabilities clearly lays out a view of individuals that, as in an ethics of care, is fundamentally relational and is grounded in materiality, community, and historicity. A capabilities approach and an ethics of care approach share the following premises: human beings are fundamentally relational, they exist in a specific historical, cultural, communal context, and because of this, persons are born with ethical duties towards those with whom they
are in relation. Ethical actions should be judged based on their ability to contribute to the flourishing of those with whom they are in relationship. Within a healthcare context, good care is care that contributes to the flourishing of others while respecting and enhancing the human dignity of those for whom one is caring.42

While Nussbaum’s approach clearly lays out the specific capabilities that should be considered when approaching the question of normativity in an ethics of care, a truly just ethics of care must also find its normative grounding in a framework that centers an intersectional approach to addressing the impact of racism, sexism and other forms of oppression on how individuals are conceptualized both morally and legally, as well as the complex relationship that individual and community relationships play in one’s ability to fulfill one’s basic human rights. Reproductive Justice, a framework and movement created by Black women in the United States in response to the inability of dominant White feminist discourse to address the needs of Black women and Black communities, is a human rights-based framework that both complements the capabilities approach while also grounding the consideration of capabilities in a conception of justice that is intersectional, anti-racist, and community-based.43

Reproductive Justice (RJ) maintains three core values: “the right to have a child, to not have a child, and to parent the child we have in a safe and healthy environment.”44 Centering not only the individual’s right to make decisions about one’s own life but also “the obligation of government and society to ensure that the conditions are suitable for implementing one’s decisions,” the work of RJ theorists and activists highlights the “lack of physical, reproductive and cultural safety for vulnerable people.”45 This approach, like Nussbaum’s, sees human flourishing for all individuals and communities as the ultimate goal of ethics and society. The additional component that RJ adds to the capabilities approach is the centering of an explicitly
intersectional understanding of the ways in which social and political structures inhibit or enable specific individuals to exercise their right to make decisions about their life and to ultimately flourish.

Kimberle Crenshaw, the originator of the term intersectionality, coined the term in response to the way legal and ethical discourse has historically approached identity politics and community considerations from a single-identity lens. This single-axis approach has led to the further marginalization of individuals who belong to multiple groups that often have conflicting needs and priorities and fails to conceptualize or support individuals in their entirety. Intersectionality acknowledges the interconnected and overlapping identities that individuals possess in an attempt to more fully understand and address discrimination and injustices individuals and communities experience as a result of their overlapping identities. An intersectional approach not only benefits the individual, whose context and choices can be more fully understood, but our understanding as a whole, as the consideration of multiple identities and the way in which they impact individuals and communities leads to a more robust understanding of the impact of structural factors across race, gender, sexuality, etc.

A Reproductive Justice capabilities approach to an ethics of care is a dignity-enhancing approach in which the adequacy of care is dependent upon the extent to which one’s relationship with another and the care which results through that relationship takes into account the social and political identities of the individual and respects and enhances the dignity of the person for whom one is caring. Human dignity is respected through recognizing the fundamental ambiguity of human persons as subjective, corporeal, spiritual beings, acknowledging the role of racism, sexism and other forms of oppression in an individual’s experience and striving to support not only the physical health of patients but also emotional, spiritual, and communal health as well. In
order to better understand the myriad of dimensions that safety entails, we now turn to a consideration of what it means to feel safe.

III. What Does It Mean to Feel Safe?

*The world is not safe to live in*

- Gloria Anzaldúa, *Borderlands/La Frontera*

Safety is more than a physical state of being: it is a feeling, an embodied experience.49 While not frequently discussed in the dominant conversations regarding safety in healthcare, there are two disciplines in which robust discourse concerning the question “What does it mean to feel safe?” have been taking place: Trauma Studies and Feminist Phenomenology.

a. The Scores Our Bodies Keep: Trauma Studies and the Question of Safety

In recent decades, the study of trauma has been approached within many disciplines: psychology, philosophy, literature, and politics, just to name a few.50 While recent literature within healthcare has incorporated insights from studies regarding Post Traumatic Stress Disorder (PTSD) into a framework for approaching care known as trauma-informed care, the discussion of trauma within this section will focus on insights about safety drawn from studying traumatic events, whose occurrence may or may not lead to subsequent mental health concerns. Trauma-informed care will be addressed in a subsequent chapter of this project concerning implementing safety in psychiatric care. Generally speaking, an event can be considered to be traumatic if it is unbearable, intolerable, or overwhelming for the individual experiencing it and is accompanied by a feeling of loss of control and/or the loss of one’s world or self.51 The experience of trauma is unique in that it has very clear physiological and psychological effects.
Physiologically, when one experiences an event as traumatic, one’s nervous system is activated and stress levels increase in the body, resulting in heightened pulse, heightened levels of cortisol, shortened and rapid breath, etc. Psychologically, when one experiences an event as traumatic, the mind’s attempt to process this event can result in anxiety, hyperarousal/hyperawareness of one’s environment, nightmares, depression, and traumatic flashbacks to the event.

The study of trauma can teach us much about the nature of safety because by definition, an experience of trauma entails a loss of safety, and recovery after a traumatic event first and foremost requires a return to the ability to feel safe: in one’s body, in one’s environment, in one’s community. In his seminal text, *The Body Keeps the Score*, Bessel van der Kolk asserts that, “being able to feel safe with other people is probably the single most important aspect of mental health; safe connections are fundamental to meaningful and satisfying lives.” While it is of course not reasonable or realistic to feel safe with every person one encounters throughout the course of one’s life, it is essential that there be individuals with whom one feels safe in order to feel the freedom to create a meaningful and healthy life. When discussing safety in this context, van der Kolk defines safe relationships as relationships in which there is *reciprocity*, in which both parties are “truly heard and seen,” and in which there is a feeling of being held by someone’s “mind and heart.”

There are several significant insights we can draw from van der Kolk’s definition of safety. First, safety happens *in relationship*: in our connections with others. Second, for a relationship to be safe, there must be *reciprocity*. Within a healthcare context, the reciprocal nature of caring relationships has been explored and articulated at length by scholars such as Chris Gastmans. Gastmans emphasizes the importance of the reciprocal nature of the nursing-patient relationship in deliberating and implementing various treatment choices for the patient,
remarking that nurse and patient should engage in dialogue and attempt to understand each other in relation to their shared goal of ensuring that good care is given to the patient. In this way, caring for the individual patient is posited as a “way of relating oneself to the other” that focuses on the human flourishing of both the patient and the nurse through this relationship.\textsuperscript{57} Third, safety in a relationship entails that one is held, in one’s full dimensions as a human, in another’s mind and heart. Within a healthcare context, this being held in both mind and heart entails that one is supported in achieving recovery or the goals of treatment both medically and through technical knowledge/skill and also that one is supported emotionally and spiritually through the tending to the flourishing of one’s fundamental human capabilities to make meaning, play, and love others.

b. Feminist Phenomenology and the Question of Safety

The feminist phenomenological tradition is uniquely positioned to offer additional insights into how safe and unsafe relationships feel in a healthcare context because feminist phenomenologists have explored both what the experience of unsafety feels like and also how the experience of illness or loss of good health can entail a loss of control and crisis of self that can constitute a traumatic experience.\textsuperscript{58} Phenomenologists writing about the experience of illness have noted that the experience of falling ill or of being in an accident that requires medical treatment can cause one to feel a hyperawareness of one’s body (through pain or the fear of the consequences of a medical condition), can lead to existential crises or an experience of a lack of order or meaning in the world (as is often the case with horrific accidents or the revelation that one has late-stage cancer with a poor prognosis), or a feeling of alienation from one’s own body.\textsuperscript{59} Feminist phenomenologists have added to this discussion by highlighting the ways in
which gender shapes both the experience of illness itself but also the ways in which women are treated by medical staff due to sexism (and in many cases racism, xenophobia, and classism as well).  

Similar to discussions within trauma studies, feminist phenomenologists have highlighted that experiences of illness or of a loss of good health can lead to a state of disruption: a chaotic lack of life’s typical order that leaves one disoriented and unable to feel “at home” in one’s body, in one’s typical way of organizing conceptions of oneself and of one’s world. This experience of a loss of home, of being disoriented and fragmented, leaves one in a vulnerable state in which one feels unsafe due to the uncertainty of what the future will entail, or if one will even survive the present to see a future. As Gastmans points out, patients are vulnerable by virtue of their inability to meet their own needs in a time of illness, and this vulnerability is compounded by the inherent power imbalance of the nursing-patient relationship. Individuals who seek medical treatment enter relationships with their healthcare providers when they are at the highest potential to feel unsafe, and it is the duty and responsibility of healthcare providers to recognize the vulnerability of their patients and to respond not only to the medical conditions for which they are being treated, but to the call to help return their patient to a feeling of home within themselves, a feeling of safety—through building trust and being trustworthy, and through opening the space for their patients to reveal themselves through narrative, dialogue, and active listening.

IV. Telling Our Bodies’ Stories: The Role of Narratives in Building Caring Relationships

If a traumatic experience is a loss of safety, it is because in the experience of rupture—the disorientation and fragmentation that occurs when one is faced with threatening forces
beyond one’s control—we find ourselves alone, isolated by an experience that seems unintelligible, and therefore, unspeakable.\textsuperscript{65} An essential component of healing after a traumatic experience is a return to community, to the relationships that ground the individual in meaning and in safety.\textsuperscript{66} As has been discussed in previous sections, safety occurs in and through relationship. This section will explore a central component of safe relationship: the ability to share and hear narratives as a form of building community.

\section*{a. Trauma and the Role of Community in Healing}

One of the most insidious characteristics of traumatic events is the way in which temporality is experienced for those who undergo them.\textsuperscript{67} Trauma survivors often experience flashbacks to the traumatic event in which their mind and body relive the trauma they’ve experienced, and individuals often find themselves unable to experience the present due to being lost in the past, when they at least had a coherent sense of self.\textsuperscript{68} Like other profound moments in our lives, such as the birth of a child or the sudden death of a loved one, the experience of trauma can isolate an individual from her sense of self and also from others. When writing of her own experience of robbery and assault, feminist philosopher Gloria Anzaldúa recounts that after such a violation, “your relationship to the world is irrevocably changed: You’re aware of your vulnerability, wary of men, and no longer trust the universe.”\textsuperscript{69} The experience of trauma and violence fundamentally disrupts a sense of being at ease in the world, of feeling the way in which your life and existence are connected to others, while also splitting your sense of your self into fragmented pieces that may seem irreconcilable to one another.

Although experiences of trauma isolate the individual in their fragmentation of the self (or, perhaps, \textit{because} they do), an essential part of healing from trauma, and, in fact, the greatest
determinant of whether or not one will successfully recover from a traumatic experience, is connecting to others and finding support through being allowed to tell one’s story. As Susan Brison notes in her book detailing her recovery from trauma, *Aftermath*,

The trauma survivor must find empathetic listeners in order to carry on. Piecing together a shattered self requires a process of remembering and working through in which speech and affect converge in a trauma narrative…The communicative act of bearing witness to traumatic events not only transforms traumatic memories into narratives that can then be integrated into the survivor’s sense of self and view of the world, but it also re integrate the survivor into a community, reestablishing bonds of trust and faith in others. This passage highlights the essential role that telling one’s story plays in the potential for healing after a traumatic event. Moreover, it shows that what is at stake in telling one’s story is not only “piecing together a shattered self” but also the reintegration of the isolated individual back into a community. This reintegration occurs through the space that is opened when one is allowed to tell one’s own story to community members who are empathetic, nonjudgmental, and willing to listen to the story that is being told to them. This form of listening and allowing of space for the traumatic narrative to unfold is one way in which to hold an other in one’s mind and heart and therefore a recognition of the other in all of her human dimensions.

b. A Narrative Ethics Approach to Building Caring Relationships

As the previous sections have illustrated, telling and listening to personal narratives is an essential part of building and growing safe relationships. In the context of healthcare, the need to illicit and honor these stories is essential for two reasons: first, the vulnerable state of patients entails a susceptibility for feeling unsafe, and healthcare providers have a duty to do whatever they can to tend to the needs of their patients and support them. Second, providers and patients often hail from different cultural, social, and economic backgrounds and may not have an
understanding of the context in which the other is living. If there is not an active attempt on the part of healthcare providers to understand the worldview of their patients, it is incredibly difficult to accurately identify patients’ needs and how they should be cared for.\textsuperscript{76} If we accept, with Walker, that one’s culture shapes one’s worldview, which in turn provides the context through which individual morality and values are formed, then it is essential that healthcare providers seek to understand the perspectives and personal narratives of their patients in order to care for them as human beings and not merely bodies.\textsuperscript{77}

Rita Charon considers narrative medicine to be medicine practiced with “narrative competence to recognize, absorb, interpret, and be moved by the stories of illness.”\textsuperscript{78} As human beings, we make sense of ourselves and the world through stories, and to truly understand how to best care for another person, one must understand that person’s story. Moreover, it is through the sharing of stories that individuals grow: the more we share with and listen to others, the more we create meaning together, play together, and understand each other.\textsuperscript{79} It is in this sense that the dialogical-interpretative care promoted by care ethicists like Gastmans should be understood. Gastmans characterizes the caring attitude of the nurse as moral practitioner as a “shift that takes place from the interest in our life situation to the situation of the other, the one in need of care.”\textsuperscript{80} The nurse, as care provider with a caring attitude, must suspend concern for his or her self in attentiveness in order to perceive and understand the specific needs of the one who needs care. Moreover, the nurse must not only suspend self interest in order to address the situation of the patient, but should strive to step outside his or her “personal reference system and take up the patient’s references” in an effort to better comprehend the patient’s lived experience, world, values and goals.\textsuperscript{81} It is clear that this entry into the caring relationship requires not only attentiveness to the specific context and needs of the individual patient but a concerted effort to
go beyond the self in order to understand and connect with the patient. One does this by going beyond one’s own self and entering into the narrative worldview of the patient with the aim of understanding, supporting, and growing with the patient through this dialogical narrative process.  

Narrative is essential to the development of safe, caring relationships because it allows for communication of meaning in a manner that is coherent while still allowing for emotions to be incorporated and valued. The majority of routine communication mandated in a healthcare context could be considered “check-box” communication inquiring about symptoms, medical history and relevant medical contextual factors. This communication paints a specific portrait of the individual: one that only conveys information about corporeal aspects of the self. In narrative, this portrait becomes more complete: by listening to details of peoples’ lives that inform who they are, and, therefore, what they value and believe, healthcare providers can better treat their patients as whole human beings, in all of their dimensions, in support of all of their human capabilities. Narrative storytelling also highlights the ways in which we are connected through language and expression: when someone tells you a story about herself, she is doing so for and with you. She does so not only so that you will understand more about her and her life, but as a way to invite you into her story and to open up the space for you to invite her into yours. This invitation is another way in which caring relationships’ reciprocal nature allows for mutual growth and flourishing: when we share in each other’s stories, we create new chapters together.

V. Safety Redefined: An Ethics of Care Approach

Safety, in all of its dimensions, is a necessary foundation for achieving good care. However, it is not in and of itself sufficient: while the safety of individuals in caring
relationships must be foundational to these relationships, feeling safe does not ensure that the
care one receives will be good. In order to understand the foundational relationship safety plays
in caring relationships, it is important to understand how safety fits into a broader ethics of care
approach.

a. Safety in Relationship: The Significance of Emotional, Psychological, and Communal
Support

The dignity-enhancing care framework proposed by Chris Gastmans offers a dynamic,
comprehensive approach to understanding nursing as a moral practice. By illustrating that
nursing as a practice should consist in care, undergone as a dialogical-interpretative process that
is founded in a response to the particular vulnerability of the individual patient that aims to
promote the dignity of the patient, Gastmans articulates a framework that both centers the
particular contexts and relationships in which people seek, give and receive care while also
providing a normative grounding for caring practices through his personalist understanding of
human dignity. Gastmans positions vulnerability as the “motivation” and “raison d’être” of care,
noting that nurses often report that their sense of ethical responsibility originates in witnessing
the “bodily vulnerability” of their patients. Care should be enacted as a dialogical-interpretative
process that is founded in a concern for the vulnerability of the individual that takes place within
a relational context with an attitude of attentiveness. This caring process is undergone in an attempt to promote the dignity of the patient, which has been threatened in this state of more-than-ordinary vulnerability.91

For Gastmans, human dignity is a multi-dimensional concept that can provide a normative basis for our caring practices due to its theoretical grounding in a Personalist view of the self.92 Due to its significance as the driving force of the ethical framework, dignity as a multi-dimensional concept and the Personalist view of the self must be explored by anyone attempting to understand a dignity-enhancing care approach. Personalism seeks to articulate and understand the “fundamental and constant aspects or dimensions of the person” in order to provide a foundation for ethical actions motivated by preserving and enhancing human dignity.93

Within this framework, human dignity and the sanctity of human life is a result of humans having been created by God and in His image.94 In providing a foundational framework that centers the promotion of dignity through respect for the various dimensions of personhood, Personalism posits an ethical framework in which relationships between individuals are seen as a fundamental component of ethical action. However, the addition of the fundamental, multi-dimensional aspects of what constitutes personhood allows a more robust criteria of what acting ethically towards a person must entail.

As was discussed in Section II, the ethics of care approach adopted in this project is not grounded in Personalism, but in a Reproductive Justice capabilities approach to understanding the complex, multi-dimensional nature of human beings. As in Personalism, a Reproductive Justice capabilities approach posits human dignity as foundational to understanding humans and insists that human dignity must be respected in our treatment of one another.95 However, due to the fact that the Capabilities approach is a secular framework that does not derive human dignity
and sanctity from a Christian understanding of humans as being created in God’s image, it presents a stronger framework for adoption than Gastmans’ personalism in a pluralist society such as the United States due to the fact that acceptance of the fundamental framework underlying a Capabilities approach respects and honors spiritual and religious beliefs as a capability that should be nurtured without necessitating that any one particular religious framework be adopted. Moreover, while there are secular Personalist frameworks that do not derivate their conception of dignity from a divine source, given the historical and contemporary pervasiveness of racism, sexism and other forms of oppression within the United States, a Reproductive Justice approach to Capabilities is still a stronger foundation in which to ground our concept of human dignity because it centers the need to understand how social and political structures impact our ability to care for one another in a way that is just. These distinctions are important to understand because, while a Reproductive Justice Capabilities approach to normativity is not a Personalist approach, it can still be said to be a dignity-enhancing approach to care in which we can judge whether or not our actions are ethical based off of their contribution to the flourishing of persons in their totality, not simply their corporeality.96

Essential to a dignity-enhancing care model is also a multi-dimensional view of dignity. As already stated, Gastmans’ framework begins with the extraordinary vulnerability of the particular patient as a situation that demands care from the nurse due to the threat this extraordinary vulnerability poses to the patient’s dignity. In this way, we can say that the goal of care is to promote the dignity of the patient through engaging in a caring process that addresses and respects his or her personhood in all of its dimensions.97 Gastmans’ conception of dignity will be further explored in Chapter Three Section Ila: Dignity-Enhancing Care and Power, but for the purposes of this chapter, it is sufficient to highlight that this conception of dignity is

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multidimension, involves an ongoing dialogic engagement between caregiver and patient, and happens with and through relationships.

Within this broader framework of dignity-enhancing care, safety holds a central role. If patients, providers and family members are to be open and vulnerable in their relationships with one another, a feeling of safety amongst all parties involved must be established. Individuals must feel truly heard and seen, must know that they are being held within the mind and heart of the person for whom they are caring and who will care for them in order to fully engage in a dialogical-interpretative process of care. If one does not feel fully seen and respected, the ways in which that individual will feel able to engage in dialogue and meaning-making with those who only partially consider them will be incomplete, or, even if there is an attempt to articulate the individual’s full needs, this attempt will not be fully heard and essential information will be lost.

It is important to note here that feelings of safety in healthcare providers are essential but often need to take a different form than that of their patients. Providers occupy a position of power over their patients, and a large part of ensuring that patients feel safe is the reassurance and support of providers in situations in which it would be inappropriate for providers to seek reassurance from their patients in return. However, providers should be ensured safety through their relationships with the organizations in which they work and their professional communities. The caring relationship requires the caring professional to both have an understanding of his or her needs and to have said needs met in order to fully engage in the relationship. If a care provider’s sense of self does not contain an understanding of the ways in which identity, relationality, and happiness can be influenced by the social identities to which one belongs, this provider will certainly have difficulty identifying and understanding the ways in which the social identities of their patients shape the identity, relationality and happiness of these individuals.
Moreover, if care providers do not feel safe, they cannot fully engage in the process of ensuring that their patient feels safe, due to their own feelings of unease and threat. As van der Kolk states, safety is the most significant factor in ensuring the mental health of an individual: if providers cannot feel safe in their work environment, they will not be able to ensure the safety of their patients.98

b. Safety and Social Determinants of Health: Expanding Our Caring Networks

While hospitals and treatment centers can often feel as though they exist as islands— independent entities separate from the outside world—the care found within these institutions often reflect the social, political, and economic inequities that exist across the United States.99 As will be explored in Chapter Three of this project, there are situations in which the social power of the healthcare provider shapes his or her’s experience of those in his or her care in a way that encourages inattentiveness to the vulnerability of particular others as vulnerability, which poses a threat to safety and the achievement of good or even adequate care. However, beyond instances of moral inattentiveness, there is also the need to understand and support the broader social contexts in which patients and providers exist.100 While there has been more acknowledgement in recent years by the medical community that Social Determinants of Health (SDOH) play a central role in the health of patients and need to be factored into how we view care, there is still much work that needs to be done.101

In order to more fully understand how SDOH contributes or detracts from one’s health, Carli Friedman has compiled a Social Determinants of Health Index which considers three factors: “choice and engagement; person-centeredness; and health and safety.”102 Within these three factors, the following indicators are considered: the extent to which an individual can
“interact with other members of the community, participate in the life of the community, perform different social roles, choose where to work, choose where and with whom to live, exercise rights, [is] treated fairly, [is] respected, [has] continuity and security, best possible health, [and whether] people are safe.” Friedman found that safe relationships, integration into one’s community, and feeling of freedom to set goals and make choices in one’s personal life all resulted in higher health outcomes for individuals. While the results of this study are not surprising, the truth that they represent is often overlooked and/or not incorporated into the way in which care is practiced.

For example, a required question upon intake into a hospital is some variation of the question, “Do you feel safe at home?” This question is asked of every patient that enters the hospital, and is asked in order to assess whether or not the patient is living in an abusive environment or a situation that would make it unable for them to return. However, even if a patient’s answer to this question is “no, I do not feel safe at home,” the response at the hospital level is often inadequate. Typically, a social worker will be brought in to interview the patient and they will determine a “safe” person with whom the patient can leave when it is time for discharge. A referral may be made to a counselor or a domestic violence service, with no plan for follow-up from anyone at the hospital, or in cases in which there is extreme concern for the physical safety of the patient, arrangements may be made to have her discharged to a domestic violence shelter. This process reflects both a sole focus on physical safety (i.e. the only concern is establishing who the patient can be discharged to without meeting physical harm) and an engagement with the social life of the patient that is superficial and does not attempt to fully address the problem of the feeling of unsafety in her living situation.
Health largely happens outside of the hospital, outside of the doctor’s office.105 People live their lives within social structures that perpetuate violence, discrimination, and poverty. If we are to truly care for our patients and each other, we must engage with the factors that prevent individuals from feeling safe in their bodies, in their families, and in their communities.106 A narrative medicine approach can help us understand each other’s stories and therefore, the wider context in which we are experiencing health and illness, but there also need to be systems in place on a structural, organizational level that facilitate the incorporation of Social Determinants of Health and our communal relationships into our treatment protocols and system wide policies.107

Conclusion.

This section has considered the need for and consequences of redefining safety in healthcare to include emotional, psychological and communal safety. By recognizing both that safety is found in relationship and that a feeling of safety is a necessary precondition for engaging in a full, honest reciprocal dialogical-interpretive process of care, we can see that until individuals are truly heard and seen, are held by someone else’s mind and heart, the care which is given and received is incomplete. Through examining what the study of trauma can teach us about the nature of safety and safe relationships, we saw the essential role that narrative and community play in establishing safety: telling a story is not enough. One has to feel as though she is being heard in order to be a part of the community. The experience of illness is one that can be isolating in its disorientation and reintegration into a community is an essential part of healing. Examining these various components of safety and the role that safety plays in achieving good care allows us to see that safety is more than just the absence of unnecessary
physical harm—it is a positive state of being held in relationship that allows us to heal and grow as we care for one another.

2b. Beyond Risk Management: An Ethics of Care Approach to Safety in Psychiatric Care

Introduction.

As noted in the first section of this chapter, there have been discussions of safety within Trauma Studies that center the importance of psychological and emotional safety. However, an examination of the history of psychiatric care reveals that the ways in which safety is primarily conceptualized, and the systems in place to treat acute mental health crises, are grounded in a risk management conception of safety that views the patient herself as a threat to safety and has physical safety as its primary concern and orienting force.

I. The Role of Risk Management in Shaping Safety

While discourse surrounding safety in psychiatric care may at first glance appear to mirror the negative conception of safety discussed in the Section 2a of this chapter in its focus on preventing the physical harm of the patient, there is an important addition to this concept of safety within psychiatric care that must be explored: the notion of patient risk.


Foucault begins *Madness and Civilization* by noting that, following the disappearance of leprosy at the end of the Middle Ages, the severely mentally ill – or “madmen”- came to occupy the social position that those afflicted with leprosy once held.¹⁰⁸ Just as those experiencing
leprosy were exiled from communities for fear of the spread of their disease, those considered mad were driven out of communities and were often made to wander outside of city limits. While the relationship between “madness” and everyday society changed throughout the end of the Middle Ages, the Enlightenment, and the 19th and early 20th centuries, one central component of this relationship remained constant: individuals experiencing severe mental illness were consistently removed from the rest of society. Over time, this exile transitioned from a physical removal from the city itself to a removal from society to jails, labor “hospitals” that primarily served as work camps, and eventually to asylums. As the physical form this exile took changed, so did the justification for this separation of the mentally ill from the broader community. While earlier forms of exile had varying motivations, in the height of the era of asylums (end of the 18th century to mid-20th century), the primary motive and justification for this separation was **fear**. Fearing the mentally ill and unequipped to adequately care for them, societies began developing institutions to house them. Even with the emergence of psychiatry as a burgeoning field in the mid 19th century, asylums largely did not seek to treat the severely mentally ill but rather, to cage them in an attempt to protect the rest of the society from the “madness” they feared. It is within this historical context that the notion of patient risk should be examined and understood.

Patient risk can be defined as “the harms a patient *creates* within the environment including violence, aggression, self-harm or suicide [emphasis in original text].” In contrast to other types of risk management strategies employed in a healthcare setting, patient risk focuses on the potential for the patient herself to pose a threat to her own safety, the safety of staff, and the safety of other patients. Moreover, in an inpatient psychiatric setting, this risk is extended to include the potential to harm not only individuals within the hospital, but the general public.
This potential risk of bodily harm to oneself or others is the criteria through which individuals are determined to be appropriate or inappropriate for inpatient treatment. If a patient has been assessed as needing inpatient care, it has already been determined that they pose a risk to the health of themselves or others and that the role of inpatient staff is to prevent their patients from committing harmful acts through risk management interventions.\textsuperscript{113}

While the notion of patient risk and the risk management strategies of inpatient staff may at first appear to be unproblematic, an exploration of the history of safety as the identification and management of patient risk as a product of institutionalization reveals that this approach to psychiatric care justifies the unethical treatment of patients, places inpatient staff in a “custodial” position that negatively influences the therapeutic bond between staff and patient, and inhibits individuals’ ability to receive adequate care.

b. Beyond Institutionalization and Risk Management

Within the context of the history of mental health treatment, Institutionalization refers to the way in which individuals with severe mental illness were “institutionalized” by being removed from their communities after an acute incident and placed in large state mental hospitals, usually for the remaining duration of their life.\textsuperscript{114} For many, institutionalization and the use of these large state mental hospitals was seen as the 20\textsuperscript{th} century iteration of the asylums of the 19\textsuperscript{th} century. Patients experiencing severe mental illness were placed in what Erving Goffman refers to as “total institutions”— institutions whose “character is symbolized by the barrier to social intercourse with the outside that is often built right into the physical plant: locked doors, high walls”\textsuperscript{115} and whose totalizing, impersonal nature often led to undignified treatment in which “the deviant person is locked into a degraded, stigmatized, deviant role.”\textsuperscript{116}
Institutionalization, particularly in the context of the United States, began to be recognized as an inhumane and ineffective treatment in the 1970s and 1980s, and a movement to deinstitutionalize mental health treatment began to gain traction. Proponents of deinstitutionalization argued for community-based mental health treatment that would provide opportunities for individuals with mental illnesses to receive care while remaining a part of their community, engaging in meaningful work and relationships to the best of their abilities, and respecting their human dignity.117 Unfortunately, as will be discussed further in the subsequent sections of this chapter, while the deinstitutionalization movement achieved its aim of releasing individuals from the large state mental hospitals, lack of funding, continuing stigma against those experiencing severe mental illness and other contributing factors resulted in a lack of outpatient treatment options for those experiencing severe, persistent mental illness compared to the overall need for these services, fragmented care continuums for individuals who need varying levels of treatment, and an overall extremely weak infrastructure to support the treatment of individuals with mental health needs in outpatient and community-based settings.118 Moreover, deinstitutionalization led to the closure of state mental hospitals but did not result in fundamental shifts in how individuals experiencing acute mental health episodes are thought of within the context of patient risk.119

Within inpatient settings, patient risk is often the primary consideration and orienting concept for day to day considerations of both patients and staff.120 Due to the role that patient risk plays in these settings, nurses have adopted a dual role: both care-taker/nurse and custodian/guard to their patients.121 The nurse-as-custodian role justifies strategies that limit the autonomy of patients, such as forced medications or the use of restraints, through the rationale that constraining the individual will ensure the safety of the patient, staff, or other patients
receiving care who are put at risk by the behavior of the patient. Within the inpatient environment, physical safety is seen as not only a priority, but as the highest priority, with some prominent voices in the field going so far as to say that “the first purpose of psychiatry is to keep the patient and others safe.” While physical safety should of course be a priority of treatment, the sole focus on this particular form of safety and the overuse of restrictive measures in the name of safety are a result of stigmatizing stereotypes about individuals experiencing mental illness and run counter to the paradigm shift promised by the de-institutionalization movement. Moreover, strategies that focus exclusively on preventing physical harm in inpatient settings have largely proven to be ineffective. For example, inpatient suicide protocols that entail merely watching individual patients who are deemed at risk of completing suicide so that staff can thwart any suicide attempts a patient might undergo have been shown to be far less effective than suicide protocols that entail not merely “keeping eyes” on a patient, but engaging in conversation when appropriate, telling the patient that they have support from staff, and stating that staff is present in the hopes of being able to respond to the needs of the patient.

In order to promote environments in which patients and nurses both feel safe- both physically and psychologically- we must change the way in which safety is considered in inpatient settings to also prioritize psychological safety. This can be accomplished through building protocols for engaging with patients (particularly those who are at high risk for suicide completion) that focus on establishing and maintaining caring relationships between staff and patients, and that center efforts to incorporate patient voice into acute, inpatient mental health care. One method of achieving this change is through adopting the Safewards model of reducing conflict and containment in inpatient psychiatric care. The Safewards model empowers patients and nurses by shifting the responsibility of safety from solely staff to a model in which
both staff and patients co-create an environment of safety. Adopting a Safewards model promotes good care by re-centering care around the needs of the patient, while also highlighting the reciprocal nature of both care and building a culture of safety, and in doing so, enhances the dignity of both patient and staff. Moreover, Safewards, and other models of inpatient treatment that promote patient-centered, relational co-creation of policies, are guided by a recovery approach to mental health care. As will be discussed further in the subsequent sections of this chapter, the recovery model of mental health is a necessary orientation across mental health treatment settings because it focuses on mental health treatment as a way to contribute to the overall flourishing of the individual through empowering the individual throughout their mental health journey.

II. “An Imminent Threat to Self or Others”: Safety in the ED

Patients view the emergency department as the location to receive assessment and treatment when faced with life-threatening health conditions. However, the way in which emergency departments are currently structured not only inadequately addresses the needs of individuals presenting to the emergency department with mental health crises, but often results in experiences that traumatize these patients.

a. Towards a Critique of the Treatment of Behavioral Health Patients in Emergency Departments in the United States

The treatment that individuals experiencing suicidal ideation or who have attempted suicide receive in the ED is critical because it has been shown that a large portion of individuals who complete suicide seek help in the emergency department in the year prior to their death and
the risk of a repeated attempt is higher in the year following an attempted suicide.\textsuperscript{131} Despite the important role of the emergency department in receiving, identifying, and caring for individuals who may be experiencing mental health crises, the experience of seeking help in the emergency department is often a wholly negative experience for those in mental distress.

There are many reasons for the inadequate care that individuals with mental health needs receive in emergency department settings. ED staff are under immense pressure to see patients as quickly as possible in order to treat as many high-acuity patients in a short period of time; emergency care is “primarily governed by the biomedical model of care” which focuses on obtaining biological and pathophysiological information through the completion of biomedical tasks and tests; and many ED staff lack knowledge of mental health and the skills to respond to patients experiencing mental health crises.\textsuperscript{132} Moreover, in many cases, patients who are in acute mental distress remain in waiting rooms and common areas with other patients who are in need of medical care. These shared spaces are often loud, noisy, and chaotic, and add to the distress of the individual, particularly if that individual has a history of trauma.\textsuperscript{133} When patients are assessed and determined to need follow-up with a social worker, they are often moved to “safety rooms” where they are stripped of their clothes and given paper gowns, the walls are bare, and they are often removed from the presence of any support individuals who present to the ED with them while they wait for the social worker to return to assess them.\textsuperscript{134} These measures are taken in consideration of the physical safety of the patient: if there are no means through which the patient can seriously harm or injure herself, she can be left to her own devices while ED staff tend to other patients. While these rooms may ensure the physical safety of the patient, given that there is nothing within the room that the patient can use to harm his or her self or others, they can cause distress in patients and often (re)traumatize patients who have been
formerly incarcerated or have a history of being abused. They also often cause the patient to feel alone, uncared for, and a sense of shame.

The failure to address the needs of patients experiencing mental health crises goes beyond that of individuals explicitly experiencing suicidal ideation. Recent studies have shown that while 10% of all emergency department patients present with symptoms related to a psychiatric illness as their primary complaint, 45% of all adult patients and 40% of all pediatric patients who present at the ED have mental health conditions that play a factor in their health and wellbeing. However, hospital staff consistently report feeling “annoyed” and “bothered by” hospital patients exhibiting mental health symptoms. Moreover, the majority of hospital staff does not have extensive behavioral health education or training: in both nursing and medical school, education concerning psychiatric illnesses is only taught as one unit, the focus of which is typically diagnostic criteria and not how to respond to symptomatic behavior in those experiencing mental illness.

The lack of behavioral health education for hospital staff is problematic for the following reasons: a) due to misunderstandings about mental health crisis, these situations are often not taken as seriously as other crises, b) lack of education about behavioral health symptomatology and how to care for individuals experiencing behavioral health crises can exacerbate symptoms in patients while also leading to caregiver distress, c) symptomatic behavior is often misread by hospital staff as being volitional and/or is misunderstood in a manner that creates fear in hospital staff, d) patients can feel dehumanized and disrespected by hospital staff during their stay; and e) the sole focus on the physical safety of patients can not only contribute to the feelings of dehumanization in patients but can also exacerbate mental health crises and symptoms.
Studies have shown that 75% of patients who are experiencing behavioral health crises can be returned to baseline within 24 hours of the onset of the crisis when properly treated.\textsuperscript{140} This is in part due to the fact that the majority of individuals experiencing behavioral health crises experience them due to depression, anxiety and/or a reaction to stress.\textsuperscript{141} While individuals who are experiencing psychosis or have a bipolar disorder will often not be able to return to baseline until they are given antipsychotic and mood-stabilizing medication, other mental health crises can typically be resolved through effective communication and administration of psychiatric medication (e.g. anti-anxiety medication, etc).\textsuperscript{142} However, in all forms of behavioral health crises, even those in which anti-psychotic and mood stabilizing medication will be integral to the treatment of the patient, the attitudes and behaviors of hospital staff are essential in influencing patient outcomes.\textsuperscript{143}

In this way, behavioral health crises are unique: while we would always assert that hospital staff should display appropriate and kind attitudes and behaviors towards all patients, in the case of behavioral health crises, the attitude and behavior of staff can directly determine the timeframe of the crisis and the potential outcome of the crisis (i.e. whether or not the crisis will lead to inpatient psychiatric hospitalization). Unfortunately, studies have shown that the majority of nursing and physician staff have negative attitudes towards behavioral health patients.\textsuperscript{144} These negative attitudes are also often reflective of racial and ethnic biases held by hospital staff, and lead to inequitable distribution of measures such as the use of restraints and sedatives instead of pre-emptive verbal de-escalation in response to patient agitation.\textsuperscript{145}

b. A Dignity-Enhancing Approach to Crisis Behavioral Health Interventions
While the current model of care for individuals presenting to the ED with behavioral health crises is inadequate due to its over-emphasis on maintaining only the physical safety of the patient while neglecting psychological and emotional safety and is made worse by staff who are under-educated about mental health and appropriate interventions for these patients, this does not have to be the case. A qualitative study exploring the experiences of individuals who sought help for suicidal ideation in the ED found that these individuals reported wanting “a sustained, productive, constructive relationship with someone who can help” during their ED visit. In order to understand what a “sustained, constructive relationship with someone who can help” means in this context, the narrative description of the experiences and desires of patients need to be explored and interpreted.

Interpersonal and systemic factors affect the extent to which patients feel they have been cared for in a sustained, constructive, helpful manner. From an interpersonal perspective, patients report that expressions of sympathy and empathy from ED staff, speaking to the patient in a soft voice and explaining why the specific questions staff were asking patients were being asked, being kind and responsive to any support individuals who presented to the ED with the patient and being able to remain in the presence of their support individuals were all noted as factors that improved the experience of individuals experiencing suicidal ideation who presented in the ED. On a systemic level, detailed mental health assessments where patients were asked a series of thoughtful questions and were listened to and given time to respond were perceived more favorably than brief, transactional discussions with social workers. Patient involvement in discharge decisions were also seen as preferable to discharge protocol that was determined solely based off of the completion of a series of brief interviews with ED social workers.
Collectively, the experiences that patients described as positive exemplify a dignity-enhancing approach to behavioral health interventions in the ED. Within this dignity-enhancing approach, the context of the patient’s mental distress is taken into consideration in the manner in which staff speaks to them (e.g. softly, in an area removed from the general chaos of the ED but with a support person present) and the evaluation of the individual is approached as a relationship in which the patient—an individual deserving of respect—is approached with curiosity and cared for as a person instead of only being viewed as the culmination of their symptoms. In a cultural context in which mental illnesses are still stigmatized, it is important that patients experiencing mental health crises are not reduced to their symptoms and are given the opportunity to co-create their own discharge or treatment plans moving forward.

In order to move towards the implementation of this type of approach as a common practice, hospitals need to implement the following: staff education about behavioral health and racial and ethnic biases in responding to patient agitation and distress, streamlined processes for triaging individuals experiencing mental health crises from other patients while still allowing them to be in the presence of a support individual or providing them with a support individual (for example, a peer support specialist), and policies that explicitly incorporate patient feedback into hospital discharge plans. To aide in implementing these considerations, the following recommendations should be considered. First, hospitals can offer ongoing staff education via lunch and learns and online and in person Continuing Education Courses on appropriate care for treating specific mental health diagnoses that frequently occur in a hospital setting (i.e. personality disorders, depression, anxiety, psychoses, bipolar disorders, etc). Second, hospitals can incentivize gaining this education by offering slight pay increases to medical staff who complete additional behavioral health education (i.e. a certificate or a certain number of credit
hours in psychology) in a manner similar to how displaying fluency in a second language is recognized as a specialized skill that should be compensated as such. Third, hospitals can have basic Mental Health First Aid trainings as a part of the onboarding process for new hires. This would ensure that all incoming hospital staff at least have a shared foundational set of knowledge and skills for how to intervene when patients who are experiencing a behavioral health crisis arrive at the hospital. It is also essential that the education provided to hospital staff should have an emphasis on strategies for interventions and care, not only the diagnoses themselves, as studies have shown that nursing and physician staff often have a clear understanding of the diagnostic criteria for psychiatric illnesses but do not have knowledge of best practice interventions for their patients experiencing these psychiatric illnesses. This education should also explicitly have an emphasis on understanding how implicit bias and structural racism impacts both the perception of mental health symptoms and the interventions offered to patients and families.

Finally, having Peer Support Specialists/Peer Navigators present in the ED and assigned to specific patients in the hospital with acute behavioral health needs will not only help reduce feelings of isolation and dehumanization in patients with behavioral health needs, but peer professionals can also serve as an educational resource and consultant for clinical staff who may not know how to intervene with a patient or may not understand the ways in which their behavior may be perceived as disrespectful or dehumanizing by patients. By supporting these efforts in improving both interpersonal and systemic response to mental health crises in the ED, hospitals can fully utilize the ED as a resource to support patients experiencing life-threatening conditions.
III. Redefining Safety Across the Continuity of Care

Relational, dignity-enhancing care that centers the importance of supporting psychological safety and meaningful contributions of the individual to her own life and treatment are essential in acute, crisis situations. However, in order to support the long-term health and wellbeing of individuals with severe persistent mental illness and to prevent unnecessary crises from occurring, it is also essential that this approach be adopted within outpatient settings and across the continuity of care for this patient population.

a. The Impact of Safety in the Outpatient Treatment of Individuals with Severe Persistent Mental Illness

While there are various mental illnesses that have severe, long-term impacts on individuals’ lives, this subsection and the following subsection of this chapter focus specifically on psychotic disorders as an exemplary condition for both the current failures of our systems of care and the most promising solutions for improvement. In the United States, a diagnosis of schizophrenia or another psychotic disorder is typically considered to be a significant- if not primary- part of one’s identity once the diagnosis is given. It is also usually considered to be a lifelong diagnosis, despite the growing evidence that individuals can and do recover from schizophrenia and/or can experience significant alleviation of symptoms over time with the appropriate treatment plan and supportive context. In a highly individualistic society, individuals with schizophrenia are also stigmatized due to the societal expectation that individuals should be entirely self-sufficient and independent and the fact that many individuals with schizophrenia have symptoms that prevent them from keeping a full-time job.
Generally speaking, individuals in the United States with psychotic disorders are likely to find themselves socially isolated and without the help of family, without supportive or affordable housing options, and without meaningful work options that could provide them with a sense of purpose while also recognizing the constraints their symptoms may put on their ability to do certain types of tasks.\textsuperscript{150} In addition to these factors, a large number of individuals with psychotic disorders will experience homelessness due to the lack of financial and social support and the perceived threat of their symptoms. These factors all result in a situation in which patients with schizophrenia feel socially isolated, defined by their diagnosis, stigmatized by their diagnosis, and seen as unworthy due to their inability to work in a society obsessed with productivity.\textsuperscript{151} Disappointingly but unsurprisingly, given the extent to which psychotic disorders continue to be stigmatized, the justification of this continued isolation of the individual is often stated as a concern for safety.\textsuperscript{152} While individuals experiencing psychotic disorders are statistically far more likely to experience abuse and harm from others than to harm other people, fear of these specific types of mental illnesses and misinformation about them continue to perpetuate a concern for the safety of others that can lead to overly-restrictive interventions, the removal of young people experiencing psychosis from their home environments, and in some cases, the incarceration of symptomatic individuals.\textsuperscript{153}

While one would hope that the diagnosis of a treatable mental illness would increase one’s chances at receiving care and treatment that could improve one’s quality of life, a diagnosis of schizophrenia within Western countries carries with it stigma, loss of social contacts and support, poverty, and often homelessness.\textsuperscript{154} All of these factors themselves constitute further susceptibility to harm and a worsening of mental health symptoms. This creates a vicious cycle in which an individual who is already vulnerable and susceptible to harm becomes more
susceptible to further harm by virtue of their diagnosis and subsequent social treatment. In many ways, the United States continues to fail to enact the specific social actions required to address the increasingly susceptible condition of individuals experiencing psychotic disorders.\textsuperscript{155}

b. Early Intervention First Episode Psychosis: A Model for Safe, Long-term Care

In recent decades, empirical studies have established that factors such as early therapeutic and medical intervention, ongoing family involvement, empathy and sensitivity from treatment team members, and peer delivered services all greatly improve the long-term prognosis and treatment outcomes for individuals following the first onset of a psychotic disorder.\textsuperscript{156} As a result, programs throughout the United States and other countries focusing on early intervention for first episode psychosis have been developed and are successfully challenging traditional views of psychotic disorders as “untreatable” and/or a “life sentence.” These programs are unique in that they explicitly involve the participation of not only patients but family members and friends, the robust use of ancillary services, and community services. In building a network of support for patients following the first onset of a psychotic disorder, first episode psychosis programs are beginning to find ways for patients whose diagnoses have historically isolated them from society to maintain social bonds and build meaningful lives.

The traditional model of treating psychotic disorders aligns with the model of institutionalization discussed in previous sections of this chapter in that it often involves removing the individual experiencing the psychotic disorder from their family, community, and everyday life and placing them in long-term treatment facilities.\textsuperscript{157} In contrast to this, early intervention first episode psychosis programs focus on responding to individuals experiencing their first break and their families in a comprehensive, holistic manner.\textsuperscript{158} This wrap around care
typically occurs in five phases: Phase One- Assessment and Stabilization, Phase Two- Adaptation, Phase Three- Consolidation, Phase Four- Transition, Phase Five- Post- Graduation.159 The specific naming of these phrases is drawn from the Early Assessment and Support Alliance (EASA), but the structure of early intervention first episode psychosis programs largely follows the structure of the phases described, even if the language of the phases differs. These phases occur over a two year period, after which patients and families transition into situation-specific outpatient care. From the onset of engagement in these programs, patients and families (or support systems for individuals who do not have family members) are engaged individually and collectively, and an explicit component of treatment for the individual experiencing psychosis is the preservation of supportive relationships.160 A multidisciplinary team works with individuals and families to provide assessment, diagnosis and treatment planning, individual and group therapy, psychiatric medication, education and support for family members, crisis and relapse planning, education regarding legal and ethical rights, mentoring for goal setting and skill development, occupational therapy, and vocational and educational therapy.161

Long-term health outcomes for individuals who receive early intervention first episode psychosis are significantly better than those who do not receive timely treatment or who receive only medication and traditional therapeutic support.162 This, in part, can be attributed to the early intervention component of these programs: that the amount of time the individual experiences untreated psychosis certainly benefits the individual and their family. However, these programs also center the significance of providing individuals the opportunity to continue to create meaning for themselves within their families and communities. Goal setting, skill development and vocational training are as central to the care model of this approach as medication and
counseling support. Because of this, the treatment model itself shifts fundamentally from that of symptom management and risk management for the individual patient to that of caring for the individual and their primary supports, in relationship to their community, with the goal of supporting individuals experiencing psychotic disorders in creating meaningful lives for themselves. In other words, within this model, the goal of treatment is *flourishing* of the individual, with the understanding that human interaction and community are vital components in successfully performing one’s capabilities.\textsuperscript{163}

**IV. The Role of Public Health Discourse and Surveillance in Perpetuating a Risk Management Model**

“Surveillance for, detection of, and response to natural or unintentional disease outbreaks are traditional responsibilities of public health authorities, who rely heavily on health care providers and laboratories to provide timely reports on diagnoses and test results.”\textsuperscript{164} This opening sentence of the introduction of the Institute of Medicine’s 2011 report on Biowatch and public health surveillance may at first seem self-evident and unproblematic, but in fact reveals a crucial truth about the relationship between safety and surveillance under the dominant public health model of disease control in the United States.

**a. Surveillance and the Public Health Model of Safety**

Within a Public Health context, surveillance can be defined as, “the ongoing systematic collection, analysis, and interpretation of data, closely integrated with the timely dissemination of these data to those responsible for preventing and controlling disease and injury.”\textsuperscript{165} Surveillance is seen as a key strategy in disease prevention and control because it monitors the prevalence of disease in specific populations, which can inform decisions about targeted
interventions and resource allocation, and also allows for tracking of the effect of specific interventions on health outcomes within a specific population over time. The prevalence of disease within a community is surveilled through various means: at times, actively, through regular contact with health care providers, passively, through routine reports submitted by healthcare organizations, and through routine health information systems, such as the CDC’s Pregnancy Risk Assessment Monitoring System (PRAMS), which collects site-specific and population specific data on maternal health prior to, during and immediately after pregnancy. Within this overall system of surveillance, a key form of surveillance is Behavioral risk factor surveillance systems (BRFSS), “an active system…that measure[s] behaviors that are known to cause disease or injury (for example, tobacco or alcohol use, unprotected sex, or lack of physical exercise).”

Within this framework, all modes of surveillance must be linked to action that leads to disease being controlled within a population, with public health experts going to far as to say, “the fundamental principle of public health surveillance is that the surveillance should be designed and implemented to provide valid (true) information to decision makers in a timely manner,” so that this information can be used specifically to inform actions aimed at decreasing disease prevalence. This approach, particularly when it relies heavily upon BRFSS as a strategy, is one in which risk management is a central strategy: information about specific high risk behaviors in relation to specific health outcomes can be used to design interventions that target the reduction of these high-risk behaviors in specific populations.

To return to the example of PRAMS, given that maternal health is the primary focus of this dissertation and the considerations of this topic will be built upon in subsequent chapters of this dissertation specifically within the context of maternal health: this systems monitors the
The prevalence of the following health indicators surrounding pregnancy: nutrition, pre-pregnancy weight, substance use, intimate partner violence, depression, health care services, pregnancy intention, postpartum family planning, oral health, health insurance status one month before pregnancy, health insurance status for prenatal care, health insurance status postpartum, infant sleep practices, and breastfeeding practices. The CDC describes PRAMS as, “an ongoing, site-specific, population-based surveillance system designed to identify groups of women and infants at high risk for health problems, to monitor changes in health status, and to measure progress towards goals in improving the health of mothers and infants,” that accomplishes its goals by, “influencing maternal behaviors before, during, and immediately after pregnancy.” It is important to note, however, that despite the inclusion of mothers in its description of what PRAMS entails, the CDC has identified the purpose of PRAMS as, “to find out why some infants are born healthy and others are not.”

This definition of purpose is important because it highlights the orientation of this type of surveillance: prevalence in the instances of behaviors that are considered high-risk performed by pregnancy and recently postpartum women are collected so that interventions can be performed to mitigate those risks by preventing unwanted behaviors. Within a public health framework, this is directly tied to safety because public health defines itself as, “the science of protecting the safety and improving the health of communities through education, policy making and research for disease and injury prevention.” Within public health discourse, safety is discussed consistently through the lens of reducing health hazards, preventing errors that negatively impact health outcomes, and the development of policies and procedures that aim to “mitigate, reduce or control” identified risks or hazards. As we will explore further in Chapter Six of this dissertation, within the context of maternal-infant health, the emphasis has largely been one of
protecting the safety of the infant from the perceived threat of what can be deemed “high-risk” mothers. But for the purposes of this chapter, it is enough to note that a population-level approach to maternal and infant health indicators through the collection of prevalence of high-risk behaviors is used as a strategy to determine a key intervention of behavior change targeting individual mothers. Let us now consider the potential pitfalls of this approach if it does not have relationality as a primary orientation.

b. Relationships First: Integrating a Relational Conception of Safety within Public Health Discourse

There is nothing inherently wrong or unethical about considering the behavior of pregnant and postpartum individuals and the impact that behavior might have on the health of the child—it is true that there are ways in which the health and behavior of mothers have direct impact on the health of their children, and education and support around adopting healthier behaviors is needed and should be included as a part of an overarching strategy to improve health outcomes for both mothers and their children.176 However, the dominant model of infant health in the United States for decades has over-emphasized high-risk behavior on the part of pregnant individuals in a manner that not only de-prioritizes the health of pregnant women themselves, but also results in a care environment in which the actions of pregnant individuals are seen as the cause of poor infant health outcomes, even when the evidence shows that it is not.177 Moreover, this inappropriate level of blame placed on pregnant individuals in impacting the health of their child is often disproportionately distributed to women of color and Black women specifically, in a manner that disregards the impact that factors such as racism, food and housing insecurity, and
environmental injustice have on infant health in a manner in which mothers are blamed for those structural factors.178

A risk-management approach to public health surveillance and safety has resulted in pitfalls that mirror those that we have already seen in the context of healthcare: by focusing efforts on reducing high-risk behavior or on reducing prevalence of disease (particularly for health conditions that are non-communicable, such as hypertension and substance use disorders, which are two of the leading causes of maternal mortality in the US), public health strategies at times miss the opportunity to create proactive systems of support for the communities whose health they aim to serve. Many of the health indicators monitored by PRAMS are intimately connected to structures and factors outside of women’s control: behavioral health conditions such as substance use disorders and depression are often worsened by life changes such as loss of job or housing insecurity, intimate partner violence, which is a relationship dynamic that often worsens and escalates during pregnancy, and access to adequate prenatal care, which can be largely impacted by geographical location, number of providers in your area, and access to unbiased care.

A relational public health approach to safety is necessary because the factors that influence the health of individuals and communities are directly related to the environments in which they live and the social determinants of health that help or hinder the promotion of health and flourishing.179 Analysis and programming that only targets the “high-risk” behavior of individuals and does not include attentiveness to the overall self-identified goals and desires of individuals and communities as a whole fail to improve the health of targeted populations because they fail to incorporate a partnership with communities that is truly responsive to the needs of the whole person. Rather than centering efforts that have monitoring and developing
programs around negative behaviors as their key strategy to inform policy and intervention, public health authorities could incorporate strategies that center the monitoring and development of programs that identify and promote healthy and desired behaviors and health outcomes in communities. This could entail modification of current systems such as PRAMS to highlight positive behavior change and the conditions around which this change was possible and then build strategies around supporting this type of change. For example, instead of monitoring how many women smoked during their pregnancy, PRAMS could monitor how many women gave up smoking during their pregnancy and could engage this group of women to better understand what factors led to them to want to make this change and allowed them to be successful in making this change.

As we have seen through early discussions of safety in this chapter, safety is a robust, full state that contains more than just the absence of harm. Our public health safety strategies need to support an overall strategy of safety in healthcare that recognizes and fights for a positive conception of safety for all communities in a manner that involves directly partnering with communities in creating and enacting strategies to improve population health and promote the flourishing of communities.180

V. Beyond Behavioral Health: How Redefining Safety in Behavioral Health Can Impact Healthcare as a Whole

The following case study is presented as an opportunity to consider the impact that the dominant behavioral health definition of safety can influence healthcare institutional policies. While there are other ways in which behavioral health concepts influence healthcare as a whole,
for the purposes of this dissertation in particular, the case study at hand was chosen to illuminate specific impacts this conception of safety can have in the context of childbirth in particular.

a. The Impact of Behavioral Health Policies on Healthcare Institutional Policies

In order to preserve the confidentiality and anonymity of the hospital at which this case study occurred, identifying characteristics have been removed from this case study. However, this case study and the policy discussed therein are drawn from real events.

Case Study

Hospital A had an incident occur wherein an adult patient was able to procure illicit opioids while receiving care at the hospital and passed away following an overdose on the opioids he consumed while under the care of the hospital. As a result of this incident, the hospital implemented an organization-wide policy that any patient who indicated a past or current use of illicit substances, regardless of the substance of use, would be placed on a “high-risk substance use plan.” This plan is modeled off of the intake procedures for inpatient behavioral health, and entails the removal of the patient’s personal items, including their clothing and their phone, a physical search of the patient, and the prohibition of any guests or support individuals while the patient is under the hospital’s care. Because this policy was implemented across the hospital, the plan also extended to patients admitted to the hospital in order to give birth. Laboring individuals who arrived at the hospital with husbands, parents, etc. and were honest about their past or current substance use were automatically placed on the plan, which required their support people to leave without any way for them to be contacted, given the removal of the patient’s phone, and the extent of the “physical searches” were often intrusive and dehumanizing, with at least one patient reporting having a cavity search done while receiving an epidural. Patients could be removed or stepped-down from the plan, but this required consensus from a multi-disciplinary team of providers, nurses, psychiatrists, and social workers. Given the urgent nature that childbirth often entails, not every patient was able to be taken off the plan prior to delivering their child. Moreover, when discussing this plan with nursing staff, nurses reported that adherence to the plan was incredibly variable, with the experiences of
patients largely determined by which provider they happened to get upon admission. When asked why the plan was implemented, leadership responded that the plan was in place to “keep patients safe” and prevent overdose death.

The policy described in this case study is one example of how the concept of safety as merely the absence of preventable physical harm can be adopted and misused in order to justify the mistreatment of specific patient populations. The high-risk plan was developed as a means to “keep patients safe” from themselves and others who might provide them with substances by removing all physical means through which a patient might procure substances. Within this context, there was no additional evaluation of patients to determine whether or not they would meet formal criteria for being “a risk” to themselves, nor were other measures taken such as implementing a safety plan with patients as a mitigating step that would need to be broken prior to being put on the plan. Within this context, the existence of substance use disorder in a person’s history was deemed as enough proof that they are a risk to their own life and therefore the removal of possessions and of social supports is considered justified. Moreover, this plan applied to all substances, even those for which overdose death is not a substantial threat.

While the high-risk plan constitutes a violation of human rights across the hospital, its impact in the context of labor and delivery is especially nefarious. Studies have shown that, “mothers who have the support of a companion during labor and delivery experience fewer childbirth complications and less postpartum depression.” By denying a laboring patient access to a support person, the hospital places the patient at higher risk for adverse health outcomes and denies them deserved support. When adopted as a dominant response to considering patient safety when the patient herself is considered a risk, a behavioral health definition has the potential to serve as the justification for patient mistreatment and the violations
of human rights, which can have both immediate negative impacts on the health of the individual as well as long-term negative impacts on the overall health of the mother-baby dyad.\textsuperscript{182}

\textbf{b. A Way Forward}

Creating robust systems of care requires co-creation with the individuals and communities whose health those systems are built to support. In the context of behavioral health, patients have often been excluded from contributing to the shaping of their care due to the perception that they are a risk to themselves and others. Even in contexts in which the assessment that one might be at risk of harming themselves or another, there are ways in which healthcare organizations can be more attentive and collaborative with communities in addressing their needs and desires for their health and treatment. Chapter Three of this dissertation will explore ways in which this might be approached within an individual caring provider-patient relationship, Chapter Four will explore ways in which this might be incorporated into statewide efforts to improve maternal health outcomes, Chapter Five will explore ways in which this co-creation and collaboration can be used to inform better reimbursement strategies and quality measurement and improvement efforts, and Chapter Six will expand upon the consequences that the risk-management concept of safety has had in the mistreatment of families effected by Substance Use Disorders in pregnancy specifically. Because the further details of these various ways in which a robust, positive concept of safety can be understood and pursued will be discussed in these chapters, we will not discuss them at length here. However, for the purposes of this chapter, it is essential to reiterate that in order to build systems of care and cultures of care that promote and support the overall health and safety of individuals and communities, we must have a concept of safety that is inclusive of all dimensions of safety and that recognizes that
creative, dialogical engagement with the recipients of health care is a vital component of providing dignity-enhancing care.
Conclusion

The way in which safety has been defined within healthcare has had serious consequences, both in behavioral health and in healthcare as a whole. By building systems of care around a negative conception of safety that entails only the physical safety of the patient and the reduction of preventable errors, the resulting systems have failed to identify and respond to the needs of patients, healthcare workers, and communities. If we are to truly improve the ways in which we care for one another, we need to begin to create systems that are designed to promote the full safety of the individual and the safety of communities as well. A multi-dimensional, robust conception of safety is needed to ground and inform the ways in which care is conceptualized and designed.
Chapter 3: Safety and the Significance of Moral Attentiveness

Neither love nor terror makes one blind: indifference makes one blind.

- James Baldwin

3a. Examining the Role of Moral Inattentiveness in Perpetuating Racial Disparities in Maternal Mortality

Introduction

This chapter will illustrate the significance of moral attentiveness in both safety and in a dignity-enhancing care ethics approach to maternal health and will argue that a more robust examination of the ways in which imbalances of social power and privilege across gender, race and language encourage and shape the inattentiveness of nursing staff when caring for patients belonging to an oppressed social group will both strengthen a dignity-enhancing approach to providing care while also allowing us to understand how and why the care that these patients receive often fails to achieve the goal of enhancing dignity.

I. Ethics of Care and the Problem of Moral Inattentiveness

Ethics of Care is a distinct ethical approach in that it begins its analysis with a consideration of the unique, concrete needs of interdependent individuals who have a relational responsibility to care for one another. Due to this starting point, it is essential that any individual seeking to provide care for another person must have the ability to recognize the needs of the individual for whom he or she cares as needs and must acknowledge that it is his or her responsibility to attend to these needs.
a. The Ethical Significance of Attentiveness within an Ethics of Care

In her pivotal text, *Moral Boundaries: A Political Argument for an Ethic of Care*, Joan Tronto identifies four ethical elements of care: attentiveness, responsibility, competence, and responsiveness. Of these four elements, Tronto highlights the significance of attentiveness in initiating caring processes, given that care “requires the recognition of a need and that there is a need that be cared about.” Within her analysis, not only does failure to recognize the needs of others constitute a moral failing, but attentiveness to the needs of those around us is recognized as a difficult and noble pursuit that, when successfully completed, is a moral achievement. For Tronto, this attentiveness is marked by an “absence of will”- an ability to suspend one’s consideration of personal goals, plans and thoughts about oneself for a long enough period of time in which to “recognize and be attentive to” the individual, concrete needs of others. Tronto notes that while this need to suspend our considerations of our own self in order to fully receive and acknowledge another person may come easily and intuitively to certain individuals in particular relationships, individuals often do not engage in this absence of will when confronted with the needs of others, and, moreover, often do not see the need to do so.

The problem of how to motivate individuals to acknowledge the consequences of their actions for others and their ethical duty to consider the needs of others is not unique to an ethics of care and has in fact been pondered by philosophers from Plato to the Frankfurt School. However, its significance for an ethics of care approach cannot be understated, given that attentiveness to the needs of others is essential in initiating a caring process and that ethics of care posits the caring relationship as the primary site around which all other ethical considerations are organized. While other ethical frameworks may have additional theoretical
resources to motivate individuals to engage in moral action (i.e. human rights, the common good, utilitarian considerations of the greatest good for the greatest number, etc.) an ethics of care posits that the motivation to engage in caring relationships is derived from the fact that the need for care is universal and that we therefore have an ethical duty to care for those who need us.191

Moreover, the problem of moral inattentiveness is of particular concern for Tronto as a political theorist given that the distribution of attentiveness to needs often is informed by and reinforces social inequalities.192 She states: “that ‘others’ matter is the most difficult moral quality to establish in practice.”193 This difficulty is compounded by the fact that the ability to recognize what the needs of others entail and how to respond to them always takes place within an ongoing process of “needs interpretation.”194 Individuals who are members of a dominant social group have the most difficulty in both recognizing that those with less power have ethically significant needs and in engaging in the needs interpretation process in a way that does not simply serve to benefit those who already have more power.195 Tronto believes that an ethics of care approach can more quickly identify instances in which those in power are attempting to manipulate an interpretation of needs, but also insists that the problem of privileged irresponsibility is a major concern for pursuing equitable care for all individuals in a society, and is one of the primary reasons she maintains that the needs of individuals always be understood within their political context.196

In addition to the difficulty that privileged irresponsibility and power imbalances present to the needs interpretation process, the process of recognizing and being attentive to the needs of others can also be hindered by situations in which those seeking to provide care have not had their own needs met in a sufficient manner that would allow them to be attentive to the needs of others.197 On a very basic level, if an individual has not had his or her needs met, he or she is less
likely to have the capacity to notice the needs of others, given that the immediacy of his or her unmet needs occupy the majority of the time, energy, and emotion at hand. An individual can also fail to understand his or her own needs, and through this lack of self understanding, is inept at how to recognize and understand the needs of those he or she encounters. In these ways, one’s ability to be attentive to and responsible for meeting the needs of others can heavily depend upon one’s ability to understand and care for one’s own needs.  

Although he does not use the vocabulary of attentiveness, the importance of recognizing the specific, concrete reality of the other as a call to ethical action is also discussed at length in the works of Emmanuel Levinas. While not a care ethicist, Levinas can be said to posit an ethics of responsibility: an ethics founded upon intersubjectivity and an ethical responsibility for the other who calls the subject to ethical responsibility and action through an encounter with the Other’s face. Like Tronto, Levinas emphasizes that ethical responsibility arises out of the relationship between specific individuals in concrete circumstances; one cannot anticipate the arrival of the Other or know in advance who this person may be and what he or she may need from you. For Levinas, the corporeality vulnerability of the other in particular calls the subject to action in a “face to face” confrontation that takes place through language, through a speaking. This description of the encounter with the face of the Other as the call to ethical responsibility can add to Tronto’s analysis of attentiveness because it emphasizes the importance of language in the ethical encounter with the face of the Other and underscores the significance of corporeal vulnerability as a situation that demands attention.  

From both Tronto and Levinas’ writings, we can see that an attitude of attentiveness is pivotal in initiating caring for another person, that the individual’s capacity to be attentive to an other is shaped by political, social, cultural and linguistic factors that can aid or hinder one’s ability to be attentive to
particular individuals, and that one’s ability to be attentive to the needs of others also largely depends on whether or not the needs of the potential care provider have been met.

b. Professional Power Imbalances in the Nursing-Patient Relationship

When articulating his view of nursing as moral practice, Chris Gastmans defines nursing as “the totality of skills and attitudes (caring behavior) that are applied to the context of a particular caring relationship, with the intention of providing ‘good care’ (the goal) to the (usually sick) fellow person.” [Emphasis in the original text]203 From this definition, it is clear that nursing constitutes a practice that requires both technical expertise and the cultivation of moral attitudes in response to the vulnerability of the particular patient in one’s care. It is indeed due to the necessity of cultivating moral attitudes towards one’s patients that Gastmans establishes nursing as a practice instead of a technique, which would require only technical, instrumental skills.204 Within this moral practice of nursing, Gastmans also emphasizes the importance of the reciprocal nature of the nursing-patient relationship in deliberating and implementing various treatment choices for the patient.205 The nurse and patient should engage in dialogue and attempt to understand each other in relation to their shared goal of ensuring that good care is given to the patient. In this way, caring for the individual patient is posited as a “way of relating oneself to the other” that focuses on the human flourishing of both the patient and the nurse through this relationship.206

This reciprocal relationship between nurse and patient is also defined by a particular sense of ambiguity: on one hand, nurse and patient can be seen as unified entities through their identification with one another and their shared goal of ensuring good care for the patient, but on the other hand, nurse and patient must be recognized as separate entities with different lived
experiences, different points of view, and sometimes different beliefs. As such, the caring process must always be mindful of the unique individuality of nurse and patient while nurturing both individuals. Most importantly, “caring always means helping the other to grow.” This conceptualization of the caring relationship echoes Tronto’s insistence that one’s capacity to give care depends upon whether or not one’s own needs have been met by insisting that a nurse’s ongoing concern for the development of the patient as a human being must also be tied to a commitment to self development on the part of the nurse. By caring for the patient, the nurse develops as a caring individual, and this development over time allows the nurse to provide more care and better care as he or she develops her practice as both someone who helps the patient and someone who teaches and coaches the patient so that the patient can become more self-reliant and can grow.

Again echoing Tronto, Gastmans characterizes the caring attitude of the nurse as moral practitioner as a “shift that takes place from the interest in our life situation to the situation of the other, the one in need of care.” The nurse, as care provider with a caring attitude, must suspend concern for his or her self in attentiveness in order to perceive and understand the specific needs of the one who needs care. Moreover, the nurse must not only suspend self interest in order to address the situation of the patient, but should strive to step outside his or her “personal reference system and take up the patient’s references” in an effort to better comprehend the patient’s lived experience, world, values and goals. It is clear that this entry into the caring relationship requires not only attentiveness to the specific context and needs of the individual patient but a concerted effort to go beyond the self in order to understand and connect with the patient. In this sense, the work of Levinas can again be helpful. Given that the face of the Other is revealed to the subject through language, through speech, the face of the
other can be experienced as an expression. The responsibility of the subject, therefore, is to listen to the speech of the face of the Other and to engage in language with the aim of better understanding the needs of the Other and the ways in which these needs may be addressed.\textsuperscript{213} Significantly, this encounter with the face of the Other always calls the subject into question, challenges the completeness of the individual.\textsuperscript{214} In order to become fully aware of the needs of the Other, one must go beyond oneself in this questioning of the self, which can invoke fear, uncertainty, and uneasiness at a lack of control or dominance over a situation. It is this calling into question that can lead individuals to turn away from those who need their help, but it is also this calling into question that allows for the growth of the individual providing care over time.

Recognizing the importance of cultivating a caring attitude in nursing professionals is also essential given the inherent power imbalance in the nursing-patient relationship. As Gastmans points out, patients are vulnerable by virtue of their inability to meet their own needs in a time of illness, and this vulnerability is compounded by the inherent power imbalance of the nursing-patient relationship.\textsuperscript{215} Patients count on nurses not only to provide them with care, but to not harm them or neglect them. This professional power imbalance is also constituted in the nurse’s specialized knowledge and skillset: not only does the nurse have the ability to attend to the needs of a patient in the way the patient cannot, the nurse also has specialized knowledge of medicine, the particular tools and techniques related to patient care, and the inner workings of the hospital. This specialized knowledge and skillset also results in a power imbalance in the relationship between nurse and patient because the patient relies upon the nurse to not mislead him or her, to perform technical procedures in a competent way, and to aid him or her in navigating the hospital system. For these reasons, trust and trustworthiness are also essential components of the caring relationship between nurse and patient.\textsuperscript{216} If a patient trusts his or her
nurse, the potential for self development increases, he or she is more likely to seek and engage in
treatment, and overall outcomes improve.\textsuperscript{217} In both our professional and personal relationships,
the importance of trust cannot be underestimated.

II. A Consideration of the Impact of Social Power as a Source of Moral Inattentiveness

The previous section of this paper explored the essential role that cultivating an attitude
of attentiveness plays in an ethics of care approach, the ways in which inattentiveness is shaped
by and reinforces social power imbalances, what nursing as moral practice entails, and the
significance of the reciprocal nature of the caring relationship and trust in nurse-patient
relationships due to the inherent power imbalance of such relationships. We will now turn to
Gastmans’ dignity-enhancing care framework in order to see how these considerations fit within
the caring process as a whole.

a. Dignity-Enhancing Care and Power

The dignity-enhancing care framework proposed by Chris Gastmans offers a dynamic,
comprehensive approach to understanding nursing as a moral practice.\textsuperscript{218} By illustrating that
nursing as a practice should consist in care, undergone as a dialogical-interpretative process that
is founded in a response to the particular vulnerability of the individual patient that aims to
promote the dignity of the patient, Gastmans articulates a framework that both centers the
particular contexts and relationships in which people seek, give and receive care while also
providing a normative grounding for caring practices through his personalist understanding of
human dignity.\textsuperscript{219} When articulating this framework, Gastmans focuses on three central
concepts: vulnerability, care and dignity.\textsuperscript{220} Vulnerability is central to this framework because it
is a condition which all human share by virtue of their mortality (which Chris Gastmans calls “ordinary human vulnerability”) but which can be experienced more intensely by individuals in particular, concrete way (extraordinary human vulnerability) that deserve care and amelioration from others due to the ways in which this more-than-ordinary vulnerability threatens the human dignity of the individual. Gastmans positions vulnerability as the “motivation” and “raison d’etre” of care, noting that nurses often report that their sense of ethical responsibility originates in witnessing the “bodily vulnerability” of their patients. Care should be enacted as a dialogical-interpretative process that is founded in a concern for the vulnerability of the individual that takes place within a relational context with an attitude of attentiveness. This caring process is undergone in an attempt to promote the dignity of the patient, which has been threatened in this state of more-than-ordinary vulnerability.

By beginning with the extraordinary vulnerability of the particular patient as a situation that demands care from the nurse due to the threat this extraordinary vulnerability poses to the patient’s dignity, we can say that the goal of care is to promote the dignity of the patient through engaging in a caring process that addresses and respects his or her personhood in all of its dimensions. Drawing from the work of Carlo Leget and Kirchhoffer & Dierickx, Gastmans argues that dignity is a multi-dimensional phenomenon with separate, distinct meanings and both a stable and dynamic dimension. According to Leget, dignity has remained a vague concept due to the fact that there are actually three types of dignity that are typically not distinguished from one another: subjective dignity, social and relational dignity, and intrinsic dignity (Gastmans has also referred to these types of dignity as the experiential meaning of dignity, the dignity of identity, and fundamental human dignity, respectively).
The experiential meaning of dignity is subjective and can change throughout the course of a lifetime. Leget points out that this type of dignity is not helpful for grounding moral or ethical claims because a) individuals can have false beliefs about themselves and b) in order to talk about a subjective experience of dignity, one must already bring the other two meanings of dignity into play.227 When considering social and relational dignity, Leget stresses the unstable nature of this experience of dignity: there are many people who hold positions in society that lead them to feel undignified, depressed, and useless.228 Moreover, “social and relational dignity…are dependent on cultural practices that can change” and that can at times, undermine the individual’s experience of dignity on sexist, racist, and socioeconomic grounds.229 In fact, according to Leget, the instability and potential for undermining dignity itself of the subjective and social/relational meanings of dignity is what necessitates the positing of the third type of human dignity: intrinsic, fundamental human dignity.230 Fundamental human dignity can serve as a counter-hermeneutical to the instability of the other two forms of human dignity and should be integrated within the philosophical approach of Paul Ricoeur and utilized within an ethics of care in order to answer three significant questions: 1) “What is the meaning of the concept of dignity as used by patients who express their subjective experience?” 2) “What is the quality of the caring relations in which the patient is involved;” and “What is the social position of the patient.”231 By incorporating an integrated ethics of care understanding of human dignity, dignity not only can serve as the ultimate goal of care but can be utilized as a conceptual tool to glean information and understanding of the patient’s experience as a vulnerable individual whose dignity is at risk of being harmed. The dynamic dimensions of human dignity are also significant in that they imply an ongoing process of “realizing and expressing as much dignity as possible,”
which entails a lifelong challenge to be committed to and responsible for the dignity of fellow human beings in all of their dimensions.\textsuperscript{232}

\section*{b. The Influence of Social Power in Shaping Healthcare Providers’ Capacity to Engage in Caring Processes}

Thus far, we have seen the ways in which a dignity-enhancing care approach allows nurses and patients to engage in a reciprocal caring relationship that arises out of the patient’s vulnerability and aims to promote the patient’s dignity in light of this vulnerability. This responsiveness to the vulnerability of the patient is grounded in an ethics of care which posits that individuals have a moral responsibility towards those who need care given our shared vulnerability as human beings.\textsuperscript{233} Within this framework, Gastmans articulates the need to be attentive to the inherent power imbalance of the nurse-patient relationship as both a relationship that only occurs in the context of a disproportionate distribution of vulnerability but also as a relationship in which the nurse has a knowledge and skill set that the patient most often does not. However, in order to fully understand the power imbalances of the nursing-patient relationship, we must also examine the influence that social power exerts in shaping healthcare providers’ capacity to engage in caring processes.

As Gastmans notes, the co-action and co-development of the nurse and patient effects the nurse on both a professional level and a personal, human level.\textsuperscript{234} When a nurse enters a caring relationship with a patient, she does so not only as a professional, but as an individual person who is touched by the humanity of the people she serves.\textsuperscript{235} The human aspect of the nurse-patient relationship has the potential to be one of the most transformative components of this relationship, but it also carries with it the power differentials of the societies in which this
nursing-patient relationship occurs. Gastmans notes that a central component of realizing good care within a cross-cultural context is recognizing that factors such as racism, language barriers, and xenophobia constitute an additional type of vulnerability to which these patients are susceptible.236 This insight is essential, as it establishes that the attempt to respond to the patient in all relevant aspects of his or her lived experience must occur in the context of social power imbalances that might otherwise prevent this recognition from taking place.237

However, within this analysis, the majority of recommendations given center on attitudes and practices extended towards the patient by emphasizing the ways in which attentiveness to particular cultural practices, value systems and respecting the uniqueness of the individual can improve caring practices.238 What is lacking, and equally essential to a reciprocal caring relationship attentive to the lived experience of both nurse and patient, is analysis of and recommendations regarding the role that belonging to a social group that possesses more power and privilege than that of one’s patient can play in one’s ability to recognize the needs of the patient as needs and to be capable of fully engaging in the caring process. As Tronto notes, privileged irresponsibility most frequently plays itself out in the oversight of the vulnerability of those less powerful and often shapes the ways in which the needs of the vulnerable are interpreted and understood.239 In these instances, care providers often fail to enhance the dignity of their patients due to their lack of insight into their own societal position of power and privilege. The ways in which these lacks of insights are shaped and play themselves out are deeply influenced by structural inequalities, one of the most nefarious of which is structural racism.

In “Levels of Racism: A Theoretic Framework and a Gardener’s Tale,” Camara Phyllis Jones presents a framework that understands racism as operating on three levels:
institutionalized, personally mediated, and internalized. Institutionalized racism is found in both “material conditions and access to power,” which in a healthcare setting can be seen in unequitable access to care, lack of access to education, inequitable access to resources, etc. Personally mediated racism is defined as, “prejudice and discrimination, where prejudice means differential assumptions about the abilities, motives and intentions of others according to their race, and discrimination means differential actions toward others according to their race.” Jones notes that this is the most commonly-understood definition of racism, and this is the type of racism that is most explicitly shown through interpersonal interactions. Internalized racism is defined as “acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth. It is characterized by their not believing in others who look like them, and not believing in themselves,” and an acceptance of “whiteness” as the standard to which other races should be held, while also accepting limiting beliefs about one’s own humanity and personhood. Understanding these three levels of racism and the ways in which they impact individuals’ abilities to relate to each other and even to oneself is essential in engaging in the type of caring engagement and recognition between patient and care team that a dignity-enhancing ethics of care requires because the ways in which relationships are structured and the conceptual lens through which individuals interpret their interactions in the world are shaped by all three of these levels.

III. Moral Inattentiveness in the Perinatal Period

The United States’ maternal mortality rates rank among the highest for high-income countries and the rates of maternal mortality continue to consistently rise. Vast inequities continue to exist within maternal mortality rates in the US as well, with Black and indigenous
birthing people dying at 3 to 4 times the rate of White birthing people.244 As a part of a larger strategy to understand and address the causes of pregnancy associated deaths, states have resuscitated a strategy from the early 20th century: Maternal Mortality Review Committees.

a. Inattentiveness Across Pregnancy: An Ethical Analysis of the CDC’s Report From Nine Maternal Morality Review Committees

In an effort to improve both the reporting of and response to maternal mortalities, the United States has employed a three-pronged approach to surveilling cases of maternal mortality: the National Vital Statistics System, the Pregnancy Mortality Surveillance System, and Maternal Mortality Review Committees (MMRCs).245 Of these three mechanisms, MMRCs have the greatest potential to understand and prevent the causes of pregnancy related and pregnancy associated deaths, because they involve a review of each individual case of death as well as an evaluation of root causes, preventability of death, and recommendations moving forward.246

In an attempt to understand what the collective work of individual state MMRCs could reveal about national trends in maternal mortality and potential opportunities for prevention, the CDC produced a Report From Nine Maternal Mortality Review Committees that focused on the findings of MMRCs from Colorado, Delaware, Georgia, Hawaii, Illinois, North Carolina, Ohio, South Carolina, Utah, and Virginia. This report examined pregnancy-related deaths in the prenatal period, within 42 days of delivery, and 43 days to 1 year of delivery.247 The review of each case was guided by the following questions:

“1. Was the death pregnancy-related?
2. What was the underlying cause of death?
3. Was the death preventable?
4. What were the factors that contributed to the death?

5. What are the recommendations and actions that address these contributing factors?

6. What is the anticipated impact of those actions if implemented?248

Following these guiding questions, the report found that approximately 60% of pregnancy-related deaths were preventable and that the most common factors that contributed to maternal deaths were “patient/family factors (e.g., lack of knowledge on warning signs and need to seek care) followed by provider (e.g., misdiagnosis and ineffective treatments) and systems of care factors (e.g., lack of coordination between providers),” but notes that patient and family factors are often dependent upon the latter two factors (e.g. patients may not have sought life-saving care in the postpartum period due to lack of sufficient education from their provider about warning signs or they may have been unable to do so in a timely manner due to transportation difficulties).249 The vast majority of these deaths also occurred during the postpartum period and within 1 year after delivery.

While a more thorough and in-depth analysis can be done for each individual cause of death identified within the report, for the purposes of understanding the role and impact of moral inattentiveness, we need only to look at the common themes in contributing factors for the leading causes of death. With the exception of hemorrhage, infection, and preeclampsia and eclampsia, patient/family is identified as the highest contributing factor to the leading causes of death (and was the second highest contributing factor for these causes).250 For all of the leading causes of death, patient/family, provider, and systems of care were the highest factors by far. “Patient factors” as an umbrella term cover a wide range of factors, but include factors such as patient knowledge about the condition that led to their death, patient knowledge about warning signs and the necessity of seeking care for symptoms that would indicate a need to seek care, and
the existence of chronic conditions. In the context of mental health conditions, patient factors also include, “substance use, social support, knowledge, environment, and adherence…lack of adherence to medications or treatment plans, abusive relationships and unstable housing, substance use, absence of social support systems, and not recognizing warning signs and the need to seek care.” Within this context, provider factors include, “delays in diagnosis and effective treatment, missed diagnosis, and ineffective treatment…failure to screen…failure to seek consultation…lack of communication between providers to support coordinated care and a lack of communication between providers and patients/families.” These themes illustrate that in many cases of maternal mortality, patients have not received adequate education about their health conditions and warning signs that they should seek care, do not have support systems in place to ensure that they can access and adhere to their recommended treatment protocols, and are negatively impacted by inadequate communication regarding their care. Provider failure to screen for and appropriately treat serious conditions, communicate with patients, families, and other providers about needed ongoing care all contribute to instances of pregnancy-associated death. This indicates that caring relationships, discontinuous systems of care that present barrier to access, and lack of education about health conditions and the care they might require in a manner that is supportive and effective for patients and family all contribute to the preventable deaths of pregnant and postpartum individuals.

These common themes also point to the necessity of developing an approach to addressing maternal mortality that goes beyond that of the hospital setting. While there are certainly areas for improvement need to occur on the hospital level (e.g. medical error in inpatient care, poor communication or disrespectful communication between medical providers and patients/families, etc.) many individuals are dying outside of the hospital setting in
circumstances that are caused by factors that fall outside of the scope of individual hospital teams. While everyone has a part to play in improving health outcomes for mothers and reducing maternal mortality, efforts must be made to understand how various entities across systems of care can take responsibility for the role they play in supporting or harming maternal health outcomes and then coordinating those efforts to build responsible, responsive systems of care. The failure to prevent maternal death frequently happens at the level of individual relationships, and the failure to be responsible for the part one has to play is a moral failure.\textsuperscript{254}

\textbf{b. Breakdown of Care: An Ethics of Care Analysis of Preventable Deaths in the Postpartum Period}

As shown in the previous section of this chapter, the vast majority of preventable pregnancy related and pregnancy associated deaths occur in the postpartum period. When examining the factors contributing to these deaths, it is clear that many of these deaths are a result of moral inattentiveness, disconnected systems of care, and general lack of support during the postpartum period. Continuity or care/care coordination, poor communication, and patient/family knowledge are significant factors in all leading causes of death in the postpartum period.\textsuperscript{255} When looking at these factors in the context of the \textit{leading} cause of death between 43 days and one year postpartum—cardiovascular conditions—the failure of our systems to provide adequate care for postpartum individuals and families is evident.\textsuperscript{256}

Among patient and family, provider, and systems of care factors in deaths caused by cardiovascular and coronary conditions, knowledge and communication are two of the most prevalent factor classes that cut across all three of these factor levels. When breaking these factor classes down into common themes, the following trends emerge: lack of knowledge on the part
of patients and families on warning signs that indicate emergent care is needed, lack of adherence to prescribed medications and discharge plan, lack of communication on the part of providers with patients or other providers treating their patient and a subsequent discontinuous coordination of care or lack of follow-up care.\textsuperscript{257} When patients are discharged from the hospital after giving birth, they are often understandably disoriented, overwhelmed, and frazzled. Often, even if there has been a review of warning signs of cardiovascular conditions or the need for follow-up care, this information is not retained by patients due to the overwhelming amount of information they receive and the psychological effects of the physical trauma they have undergone in giving birth. Moreover, if the patient’s experience of giving birth has been negative and particularly if she has experienced medical racism, she may also be cautious to follow up with providers who have disrespected, neglected, or mistreated her and could fear that additional medical treatment might result in further mistreatment and disrespect and the experience of mistreatment can also lead to and/or exacerbate compounding conditions, such as postpartum depression.\textsuperscript{258,259} Failure to communicate on an interpersonal level can lead to situations in which new parents are ill-equipped to recognize and respond to signs that they need help and fractured systems of care in which the ways to receive help are not clear or accessible, even if they have been identified.

Moreover, the way in which postpartum care has been structured in recent history actively withdraws care and support from new parents at a time when they might need that support most. Efforts in 2021 and 2022 to expand Medicaid reimbursement to a full year postpartum and include additional postpartum visits in the global reimbursement fee for a pregnancy episode are currently underway. These efforts have support from ACOG and other professional organizations. However, traditionally, postpartum patients receive little follow-up
on the maternal side after delivery, with one to two postpartum visits before transitioning back to primary care being the norm.\textsuperscript{260} Even if patients have been able to build rapport and a relationship with their care team throughout their pregnancy, this relationship is often not retained in the postpartum period due to these factors, and warning signs and symptoms are often missed because of these cracks in knowledge and communication.

IV. The Consequences of Inattentiveness

Statistics and data can often illustrate the breadth of a public health crisis such as inequities in maternal health outcomes, understanding the depth of the problem and the impact that inequitable care and systems have on individuals and communities can often best be illustrated through hearing and investigating the experience and narratives of individual patients and families.

a. The Role of Inattentiveness in the Death of Kira Johnson: A Case Study

“i am a black wave in a white sea./ always seen and unseen.”\textsuperscript{261} Nayirrah Waheed’s words describing the racism she experiences as a Black woman who is always watched but never truly seen can, to some extent, be applied to the situation of African American mothers giving birth in the United States. Studies have shown that the rate of maternal deaths in the United States has risen consistently between 1990 and the present.\textsuperscript{262} For every 100,000 live births, there are 14 deaths. The World Health Organization has reported that among 46 “developed” nations, the United States and Serbia were the only countries whose maternal death rates continue to rise. Within this rise in maternal death rates, it has been shown that African American mothers are approximately three times as likely to die of causes related to pregnancy
than white mothers, and the CDC has determined that more than 60% of these deaths are preventable. Many of these deaths have been directly attributed to a lack of communication between hospital staff and their patients/families, a lack of urgency on the part of hospital staff to respond to the pleas of patients, a delay in the actions of hospital staff, and patients not being listened to. Studies have also illustrated that one contributing factor to this disproportionately high death rate is the way in which unconscious bias from caregivers influences their perception of patient pain. Many providers withhold pain medication and epidurals from American women due to their perception that these women “don’t experience pain the same way.”

To illustrate one way in which these statistics are played out in individual caring relationships, we will now consider the death of Kira Johnson. Kira Johnson was a 39 year old African American woman who died following the birth of her second child, Langston Emile Johnson, of internal bleeding following a C-section at Cedars-Sinai hospital. Mrs. Johnson appeared to have a routine C-section without complications, but within an hour of her C-section, her husband noticed blood in her catheter. Once hospital staff were alerted to the situation, they were slow to respond. Following Mr. Johnson’s conversation in which he alerted hospital staff to the blood in his wife’s catheter, it took over an hour for a nurse to examine the bag and change Mrs. Johnson’s catheter. This was followed by an ultrasound that revealed signs of internal bleeding. A CT scan was ordered but never administered. According to her husband, for the four hours following the ultrasound, Mrs. Johnson appeared “pale and groggy” and “shivered uncontrollably” while hospital staff minimally engaged in conversation with her and her husband and could not answer Mr. Johnson’s repeated requests to know what was being done by staff to identify the source of his wife’s internal bleeding. Eventually, almost 10 hours after her C-section and 9 hours after her husband reported the blood in her catheter, Mrs. Johnson was taken
into surgery and died during her procedure. Her husband reported that her last words prior to entering surgery were, “Baby, I’m scared.”

Medical records and accounts from the day of Mrs. Johnson’s death that have been released as a part of a civil rights lawsuit her husband has filed against Cedar-Sinai reveal that inattentiveness and oversight were at play throughout the ordeal that led to Mrs. Johnson’s death. While Mr. Johnson pled with nursing staff to help his wife after she began showing symptoms of blood loss, a nurse told him that she was, “not a priority,” and hospital staff ignored Mr. Johnson and his mother in law’s requests to help their rapidly deteriorating loved one for the entirety of the 9 hours following Mr. Johnson’s initial request for his wife to be seen after noticing blood in her catheter. Mrs. Johnson’s cause of death was found to be internal bleeding, and it was discovered that by the time of her death, “nearly 90% of her blood was later found in her stomach…her bladder had been lacerated and she hadn’t been sutured properly.”

Dr. Kimberly Gregory, an OB-GYN at Cedar-Sinai, has supported Mr. Johnson’s claims that structural racism is a factor that prevents equitable care for Black patients on a daily basis at the hospital, and maintains that Mrs. Johnson should have been brought to the operating room in a more timely fashion. At the time of Mrs. Johnson’s death, Cedar-Sinai had already adopted the Alliance for Innovation in Maternal Health’s Obstetric Hemorrhage Patient Safety Bundle, which requires as a part of the bundle that each unit has clear criteria for assessing, identifying, and immediately responding to postpartum hemorrhage through quantitative measurement of blood loss and standardized protocols to provide blood products to patients who are hemorrhaging. There were policies, standardized practices, and algorithms in place on the unit in which Mrs. Johnson was treated to respond to patients experiencing postpartum hemorrhage: Mrs. Johnson was simply not seen as a patient who should receive those services, despite exhibiting all of the
symptoms of an individual experiencing a massive hemorrhage after a caesarean section. A c-section is a serious medical procedure, and as with all medical procedure, there are risks that the procedure may go awry. However, the death of Kira Johnson was caused not only from a poorly performed c-section, but from a prolonged refusal on the part of her care team to listen to the pleas of her family, to see her deteriorating physical condition as a sign that she needed immediate intervention, and by a failure to see her as “a priority.”

The death of Kira Johnson is a tragic example of the ways in which a lack of attentiveness on the part of hospital staff to the vulnerability of their patient can not only detract from the experiential dignity of their patient but have lethal consequences. If we examine this situation in its particularities, it is clear that hospital staff demonstrated the lack of communication, lack of urgency, and an inability to listen to the plight of Mrs. Johnson and her husband referenced by the CDC in their assessment of why maternal death rates continue to rise in the United States. Despite multiple attempts by Mrs. Johnson’s husband to engage hospital staff in conversation regarding his wife’s needs and care, these conversations were never robustly explored due to the lack of attentiveness on the part of hospital staff to the seriousness of Mrs. Johnson’s condition and the immediacy of her needs. Hospital staff also failed to recognize the severity of Mrs. Johnson’s physical state: her pale, groggy presentation and shivering should have indicated to staff that her condition was worsening, but these physical signs were not read as a signal that Mrs. Johnson was becoming more vulnerable as time progressed. The hospital staff tasked with caring for Mrs. Johnson clearly did not respect her human dignity, and their failure to do so stemmed from a refusal to view her bodily vulnerability as vulnerability and as a call to ethical responsibility. As such, the dialogical-interpretive care process was halted before it even began. It is also notable that this situation occurred at Cedars-
b. Cultivating Attentiveness of Susceptibility in Members of Socially-Empowered Groups

When considering what type of work is done in the healthcare sector, Annelies van Heijst considers the opening question of Hannah Arendt’s *Human Condition*: “What are we doing?”

van Heijst, following Arendt, believes that this is a foundational question to any consideration of healthcare, given that if we do not know what we are doing, our odds of doing things well are quite slim. The great strength of Gastmans’ dignity-enhancing care framework is that it tells us exactly what we, as caring professionals, are doing: we are engaging in a dialogical-interpretative care process in response to the vulnerability of a particular other with the purpose of enhancing the dignity of this person. In regards to nursing as a moral practice in particular, we can say that we are nurturing the growth of the patient and ourselves through caring for the patient. We do this through being attentive, supportive, responsible professionals who are worthy of trust due to our commitment to both our professional competency and our duty to enhance the dignity of our patients.

However, as we have seen in the previous sections of this chapter, there are situations in which the social power of the healthcare provider shapes his or her experience of those in his or her care in a way that encourages inattentiveness to the vulnerability of particular others as vulnerability. The question then arises: how can we cultivate the capacity to engage in caring processes in healthcare providers who have illustrated difficulty doing so, either due to unrecognized implicit bias or lack of clarity about their own unmet needs that prevent them from looking outward? I believe that three possible paths towards addressing this question are: a) the
development of a conception of self care (taken in the literal sense of engaging in a caring process directed towards the self, and not in the popular sense used contemporarily) that has as a central component an exploration of the ways in which ones subjectivity is socially constructed; b) a concerted effort on an institutional level to promote professional cultures in which the influence of social power in interpersonal relationships is openly and frequently discussed; and c) a reorientation of caring work as a practice of presence as opposed to a series of interventions. These paths will explored in depth in section 3b of this chapter.

V. Moral Inattentiveness and Severe Maternal Morbidity

While maternal mortality in the United States has received deserved increased attention in the past few years, maternal deaths are merely the tip of the iceberg when it comes to adverse health outcomes for pregnant and postpartum individuals. In order to understand the extent to which these patients and their families are impacted by moral inattentiveness, it is important to also consider severe maternal morbidity.

a. The Role of Racism in Perpetuating Disparities in Severe Maternal Morbidity

While there has not been an official definition of severe maternal morbidity issued by the college itself, the American College of Obstetricians and Gynecologists (ACOG) uses an operational definition of severe maternal morbidity as “unintended outcomes of the process of labor and delivery that result in significant short-term or long-term consequences to a women’s health.” Building upon this, the CDC has defined severe maternal morbidity as being comprised of 21 indicators: “acute myocardial infarction, aneurysm, acute renal failure, adult respiratory distress syndrome, amniotic fluid embolism, cardiac arrest/ventricular fibrillation, conversion of cardiac rhythm, disseminated intravascular coagulation, eclampsia, heart
failure/arrest during surgery or procedure, puerperal cerebrovascular disorders, pulmonary 
edema/acute heart failure, severe anesthesia complications, sepsis, shock, sickle cell disease with 
crisis, air and thrombotic embolism, blood products transfusion, hysterectomy, temporary 
tracheostomy, and ventilation.” As with maternal mortality rates, rates of severe maternal 
morbidity have steadily increased in recent years by almost 200% between 1993 and 2014. 
Within this same time period, non-Hispanic Black patients were estimated to have experienced 
severe maternal morbidity at almost twice the rate of non-Hispanic White patients.

To return the levels of racism framework proposed by Jones: racism in healthcare occurs 
on three levels: institutionalized racism, personally mediated racism, and internalized racism.

When considering inequities in broader systems of care, the impacts of institutionalized racism in 
particular are clearly seen. Jones writes that, “institutionalized racism manifests itself in both in 
material conditions and in access to power. With regard to material conditions, examples include 
differential access to quality education, sound housing, gainful employment, appropriate medical 
facilities, and a clean environment.” Systems of care and organizational structures have 
traditionally been structured to accommodate the needs of White patients, which has resulted in 
healthcare environments in which racism is sometimes directly experienced through explicit bias, 
but also in environments in which discrimination is experienced through the exclusion of 
appropriate care for BIPOC (Black, Indigenous, and People of Color) individuals and 
communities. Studies have found that Black patients receive care that is less clinically 
appropriate and lacking in meeting patient needs, that healthcare systems are more likely to meet 
Black patients through the lens of surveillance and punitive/legal lenses than through a 
therapeutic lens, and that personally mediated forms of racism result in stereotyping, 
disrespectful treatment, and the denial of certain treatment due to beliefs grounded in bias.
Women of color report instances of mistreatment from their medical providers at rates much higher than their White counterparts. Moreover, the history of reproductive coercion and eugenic practices targeting Black women and low income women have resulted in deep-seeded and justifiable distrust of healthcare systems.

These factors have all resulted in a contemporary state of maternal health where Black women have less access to care, receive lower quality of care when they do obtain access, and often experience mistreatment that feeds into and perpetuates distrust of healthcare systems and providers and can often lead to lack of necessary follow-up care. Moreover, the stress of racism during pregnancy has been shown to be linked to the worsening of several serious conditions in both Black women and their babies, such as high blood pressure and preterm birth and low birth rates. Experiencing racism has a negative impact on the body and not being heard and not being met with curiosity when it comes to ones health status can lead to the overlooking of warning signs and or to individuals falling through the cracks in our systems of care. In thinking about the current state of maternal health it is important to understand that not only are Black women dying preventable deaths throughout the course of pregnancy and the postpartum period, but Black women are also experiencing more health complications and receive less care and less quality care while they experience those complications. Racism is not only a determining factor in how women are dying; it is also a determining factor in what women are forced to experience even when they survive.

b. Where Do We Go From Here?

Moral inattentiveness towards individuals from socially disempowered groups is built into the framework of our systems of care, individual organizational policies, and individual
provider-patient relationships. Because it exists across each of these levels, our attempts to provide morally attentive care must occur across all of these levels as well. Historically, the ways in which healthcare systems and medical fields themselves were developed entailed ignoring the voice and humanity of Black patients by using them as experiments in the quest to find cures for the ailments of White patients, and our current healthcare systems and medical fields have not fully reckoned with their racist and unjust roots. These inequities have been echoed and worsened by legislation that has supported the uplifting of White communities while encouraging the ill-health of communities of color by regulating them to food desserts, encouraging red-lining, and placing them in areas of high pollution, just to cite a few of many examples.

In *The Political Determinants of Health*, Daniel Dawes expands upon Jones’ use of the image of the gardener to explain the ways in which certain communities are provided the conditions in which to flourish while others are given the bare minimum (or less) by invoking the image of an apple orchard in which certain trees are given prime conditions to grow to their full potential and other trees are planted in unfertile soil, given inadequate water and are not given the appropriate amounts of fertilizer to support their growth and production of apples. As with other systems that shape and perpetuate our society, our health care systems have been built to provide certain communities with stronger foundations of health which are only strengthened by the attentiveness of caring efforts to help meet needs as they arise. To achieve the goal of health equity, we need to rebuild our health systems, rebuild the ways in which our organizations operate, and rebuild our understandings of ourselves and our individual relationships so that the foundation of health for every community is rooted in equally fertile soil and entails ongoing care that is responsive to the individualized needs that might arise.
To echo a much-quoted sentiment from Aristotle: if the *telos* of an acorn is to grow into a mature tree and bear fruit, the *telos* of human life is to reach one’s own potential for wellbeing, where wellbeing entails, “not so much an outcome or end state as…a process of fulfilling or realizing one’s daimon or true nature—that is, of fulfilling one’s virtuous potentials and living as one was inherently intended to live.” Supporting individuals and communities in reaching their potential requires curiosity, attentiveness and responsiveness to individual needs, desires, and experiences. With this in mind, morally attentive systems must be co-created with the communities whose health is being supported and must be built around supporting their self-identified goals. Morally attentive organizational policies should be comprised of policies that arise from and are attentive to needs that have been identified by patients and communities themselves. And patients should be considered the experts of their own experience of their bodies and of their health who, in relationship with healthcare teams, receive care through the broader aim of promoting their ability to fulfil their own potential; i.e. their ability to flourish.

**Conclusion**

The violence of structural inequities is played out in individual relationships and encounters and these encounters in turn reinforce the inequities they enact. Because of this, our ethical frameworks, particularly those seeking to guide our caring practices, must explicitly include robust attempts to counteract existing societal inequities while also supporting and nurturing the cultivation of caring relationships that have the potential to subvert and dismantle the inequalities they refuse to enact. In order to do so, we must have a full examination of the ways in which power differentials and privilege across gender, race and language can shape the inattentiveness of those providing care. Making these power differentials explicit and showing
the ways in which they encourage inattentiveness will allow us to begin to address the question of how to cultivate an attitude of attentiveness in healthcare staff in a more adequate manner. Examining the influence of social power differentials on shaping attentiveness and inattentiveness in care providers also highlights the significant self-reflective work that individuals must undergo on an ongoing basis in order to be able to fully understand themselves, their own needs, and therefore, to be capable of fully engaging in caring processes that can enhance the dignity of the individual instead of detracting from this dignity or failing to engage in the caring process at all. To turn the tide on inequities in health in this country, we must build morally attentive systems of care that support individuals and communities in their flourishing.

3b. Towards an Account of Moral Attentiveness

Introduction

Examining the role that moral inattentiveness plays in contributing to contemporary health inequities is a necessary step in working to understand and eliminate those inequities, but it is only a first step. In order to move towards building more attentive, responsive caring relationships and caring systems, we must also begin to develop an approach to moral attentiveness that supports and encourages just, equitable care.

I. A Reproductive Justice Capabilities Approach to Moral Attentiveness

As seen in previous sections of this chapter, attentiveness requires that vulnerabilities requiring care and action be seen as a call to ethical engagement and an initiation of the caring process. If we are to begin to cultivate moral attentiveness—particularly for those who have
historically and contemporarily been disenfranchised and overlooked—this will entail cultivating two central components: the act of presence and the art of listening.

**a. Towards a Just Account of Moral Attentiveness**

As Dana-Ain Davis describes in her book *Reproductive Injustice: Racism, Pregnancy, and Premature Birth*, medical interactions between Black parents and care teams are often shaped by racist stereotypes and prejudices about “how” Black parents are and what their experience of pregnancy and childbirth entails. When patients are met and viewed through a predetermined conception on the part of healthcare workers, they are not seen as a unique individual who has individual needs that need to be interrogated and met: rather, their behavior, words, and perceived needs are already interpreted through a biased lens. In order to recognize the needs of an individual as needs, one must first be able to recognize the individual as an individual. In order to understand the needs of an individual, one must also be able to listen to that individual describe their experience, their goals for themselves, their care, and their life. Within an unjust social, cultural, and political context, learning how to be present with and listen to those who have often been silenced will require an active process of cultivating these two skills. While there are many ways in which this active cultivation might be approached, we will now explore four paths towards cultivating a more just practice of moral attentiveness.

The first path towards cultivating attentiveness embraces Gastmans and Tronto’s claims that the caring relationship is a reciprocal relationship that requires the caring professional to both have an understanding of his or her needs and to have said needs met in order to fully engage in the relationship. If a care provider’s sense of self does not contain an understanding of the ways in which identity, relationality, and happiness can be influenced by the social identities
to which one belongs, this provider will certainly have difficulty identifying and understanding the ways in which the social identities of their patients shape the identity, relationality and happiness of these individuals. Moreover, if care providers have not worked to understand their own personhood in all of its dimensions, they may be unfamiliar with what that process entails when attempting to co-act to enhance the dignity of their patient. Lastly, if one is to truly care for oneself, this requires attentiveness to the particular context in which one lives. Social power exerts a large influence on individuals and society, and a failure to be attentive to one’s own membership of society not only hinders one’s ability to do so for others, but also constitutes a failure to address the dimensions of one’s own personhood that relate to the historical and social being of the individual and can retract from one’s own experience of dignity. Essentially, in order to be fully present in a caring relationship, healthcare workers must first build an understanding of their own self within a social, cultural, and political context.

The second path towards cultivating attentiveness seeks to draw upon the community of healthcare providers in order to promote a more complete and caring professional culture. While a healthcare provider may not become aware of social power imbalances through his or her conversations with patients due to the professional power imbalance of the nurse-patient relationship, the relationship of co-workers who hold similar ranks in an institution does not contain the same power imbalance as the nurse-patient relationship. Because of this, co-workers are often able to articulate difficult truths and observations that patients may be too intimidated to articulate. Encouraging ongoing communication about social power differentials amongst staff can illuminate the impact these power differentials have on individual caring relationships in fruitful ways. This process of course would require that the working culture of an institution is one of trust and safety, so that individuals could feel comfortable discussing difficult and
personal insights. This strengthened co-worker culture will also promote staff’s ability to care for one another as they care for their patients.

The third path draws from Annelies van Heijst’s interpretation of Baart’s *A Theory of Presence* and requires a reconceptualization of the type of work in which healthcare providers are engaged. Van Heijst supports a conception of healthcare work that conceives of itself as a practice of presence. This conception of healthcare work will explored in further detail in the section IIIa of 3b: *The Theory of Practice: Rethinking What We Do.*

The fourth path entails cultivating a practice of *listening*. As we saw with the case of Kira Johnson, often morally significant needs are overlooked because patients and their families are not listened to when they report that they are in pain, distress, or need care. As we will see in the analysis of presence, part of remaining with and in relationship to another person is remaining *open and receptive* to that individual. While healthcare workers may have a wealth of medical knowledge and expertise, the best expert when it comes to the experience of a patient is the patient herself.

b. The Intersectional Role of Moral Attentiveness in Anti-Racist Healthcare

Moral attentiveness is a powerful tool within an anti-racist approach to healthcare because it allows the caring relationship to make visible wants, needs and aspects of personhood that might otherwise remain overlooked. Within a multi-dimensional understanding of the self, an intersectional understanding of the self and others can help healthcare teams fully engage in transformative, attentive relationships.

II. Understanding the Self, Understanding the Other
a. The Role of Self Understanding in Building Just, Moral Relationships

Kimberle Crenshaw coined the term “intersectionality” to describe the ways in which Black women inhabited cross-sectional identities by virtue of being both a part of the Black community (and therefore recipients of racism) and women (and therefore recipients of sexism).\(^{301}\) As a lawyer and legal scholar, Crenshaw’s interest was in examining the ways in which anti-discrimination laws and the theory upon which they were founded overlook and often harm Black women due to the lack of consideration of individuals who embody multiple social identities. When looking at anti-racist legislation, there was often a lack of consideration of gender discrimination that would affect Black women, and when looking at anti-sexist legislation, there was often not a consideration of race. This resulted in legislation and policy that at times supported anti-discriminatory practices for Black men and White women respectively, but did not address the discrimination that Black women faced as individuals who were both Black and female.\(^{302}\)

Crenshaw’s analysis was crucial in exploring the ways in which embodying multiple, intersecting identities can lead to specific groups and individuals being overlooked, even in attempts to eliminate discrimination and become more inclusive. When thinking about intersectionality on a more phenomenological, existential level, the work of Gloria Anzaldúa can again be helpful. Anzaldúa speaks of her experience of intersectionality as living in a type of “borderlands” between communities that she inhabits, stating, “The Borderlands are physically present wherever two or more cultures edge each other, where people of different races occupy the same territory, where under, lower, middle and upper classes touch, where the space between two individuals shrinks with intimacy.”\(^{303}\) As a lesbian Chicana woman living in Texas,
Anzaldúa found herself rejected by the dominant White communities she found herself in as an academic in Texas, and as a lesbian, she found herself rejected by the Latino community that raised her. While when overlooked, living at the intersection of multiple identities or “in the borderlands” can be a source of inattentiveness of the needs of others and ourselves, when one learns to identify and question the multiple identities one inhabits, this can be the source of invaluable knowledge about the self, social identities, and the potential for positive change.³⁰⁴ By continuing to exist in a way that resists assimilation or destruction by the communities that rejected her, Anzaldúa is on one hand harmed by oppression and discrimination, but on the other hand, is able to create herself to be something that could not have existed previously.³⁰⁵

b. Cultivating Moral Attentiveness in Healthcare Communities

While a healthcare provider may not become aware of social power imbalances through his or her conversations with patients due to the professional power imbalance of the nurse-patient relationship, the relationship of co-workers who hold similar ranks in an institution does not contain the same power imbalance as the nurse-patient relationship. Because of this, co-workers are often able to articulate difficult truths and observations that patients may be too intimidated to articulate. Encouraging ongoing communication about social power differentials amongst staff can illuminate the impact these power differentials have on individual caring relationships in fruitful ways. This process of course would require that the working culture of an institution is one of trust and safety, so that individuals could feel comfortable discussing difficult and personal insights. This strengthened co-worker culture will also promote staff’s ability to care for one another as they care for their patients.

III. Healthcare as a Practice of Presence
In order to further understand the type of presence involved in cultivating more morally attentive caring relationships in healthcare workers it is helpful to consider Annelies van Heijst’s *The Theory of Practice.*

**a. The Theory of Presence: Rethinking What We Do**

Annelies van Heijst articulates a theory of healthcare work that conceives of itself as a practice of presence. Within this self-understanding, the work of the practitioner of presence can be said to contain the following characteristics: “1) workers set themselves free, 2) workers open themselves up, 3) worker relate in an attentive way, 4) workers tune in with what is given, 5) workers are dynamic, 6) workers are at the other’s disposal, 7) workers exercise self-control, and 8) workers are devoted.” Each of these guiding characteristics is then assigned three dimensions. These dimensions provide a foundational orientation to the guiding characteristics and aide in the understanding of how these characteristics unfold in the particular context of healthcare work. The three dimensions are as follows: in order for presence practitioners to set themselves free, they must refrain from routine, withdraw from institutional pressure, and work in an open way. In order to open themselves up, presence practitioners must orient themselves towards others and making the effort to be approachable. In order to relate to other in an attentive way, presence practitioners must be uninhibited, “outgoing and alert, and [give] *substance to the contact.*” The following characteristic of tuning in to what is given arises directly out of relating to the other in an attentive way. Tuning in requires that the practitioner “will not disown the other person’s story, pain or joy, will recognize what is at stake for the other, and integrate and strengthen the existing networks of one’s family, street or club.” It is important to pause here and note that this account of tuning in provides us with a more robust understanding of what
attentiveness actually entails: being attuned to the story of another, understanding the stakes involved for that person, and working to strengthen social and relational ties.

Related to this is the following characteristic of being dynamic. The presence practitioner must strive to understand and adopt the perspective of those he or she serves, understand their reasoning, and be on their side (i.e. promote their best interest). One can be on an individual’s side by adopting the next characteristic: being at someone’s disposal. Presence practitioners should be attentive to the needs of those they serve, which means that the person they serve should be allowed to determine how the practitioner is needed. The presence practitioner will also exercise self-control, which means that the practitioner must give those they serve time and space to themselves and allow those they serve to set the pace for their interactions. Finally, presence practitioners are devoted, which means that they must be dedicated to their work unconditionally and without self-interest. Van Heijst also adds that there are both passive and active ways of embodying these characteristics. While it is clear that certain aspects of the presence practitioner approach are more conducive to nursing practice than others, a general orientation of the work of healthcare professionals as a vocation in which one seeks to become an ongoing presence in the life of the patient in a way that is attentive to the needs of the patient and is determined by the patient aligns both with a general attempt to cultivate moral attentiveness in healthcare providers and with a dignity-enhancing care ethical approach.

b. Co-Creating the Future of Hospital Politics: Lessons from the Institute of Healthcare Improvement’s Equity Action Lab

Previous sections of this chapter have explored the importance of presence in morally attentive healthcare work. However, in addition to presence, if we are to become more attentive
and more just in our attentiveness, we must also cultivate and fine-tune our ability to listen to patients, families, and communities. One attempt to center the voices and recommendations of patients into efforts to become more equitable is the Institute of Healthcare Improvement’s Equity Action Lab. The Equity Action Lab model arose out of IHI’s 100 Million Healthier Lives collaborative, a national project that aimed to improve health outcomes for 100 million individuals in the United States by the year 2020. While the Equity Action Lab in particular will be explored in this section within the context of structured, active listening, it is also important to note the conception of equity that this project centered.

100 Million Healthier Lives’ focus on equity arose from three sources: “1) a recognition that it is not possible to achieve the health outcomes we seek without addressing equity; 2) a recognition of the tremendous waste in human potential that results from inequity; and 3) a belief in our interconnectedness, common opportunity and destiny.” It is clear from these sources that equity is selected as a focus area not only because of health outcomes themselves, but from an understanding that inequitable health outcomes results in a loss of human potential which impacts all of us due to the relational, interconnected nature of human existence. Equity within this project is also not directly defined but is rather operationalized as a series of questions that arise out of the belief that “just and fair inclusion into a society in which all can participate, prosper, and reach their full potential [unlocks] the promise of the nation by unleashing the promise in us all.” Some of these questions include:

- Who isn’t thriving? What led to this and who benefits? How might racism, prejudice and power be playing a role?
- Who is thriving within the same community? How could we change the system so that these bright spots become the new normal?
- How can those with lived experience help us understand the system that is producing inequity? How might they help to create and shape the solutions?
What systems, beliefs and structures perpetuate inequity? How might these be interrupted or redesigned to create different outcomes? What will it take to create sustained improvement? Conceptualizing equity as a shared goal that is moved towards collectively, in relationship and in dialogue among communities and not only healthcare workers, the approach of 100 Million Healthier Lives establishes equity as a series of collective and individual actions whose work is never complete.

The Equity Action Lab model, which was initially developed by Community Solutions, was adapted for the 100 Million Healthier Lives due to its focus on a series of structured activities performed by “a diverse group of community stakeholders to take action in pursuit of equity and community improvement” and uses “human-centered design principles, which puts the people most affected by the inequities, or the problems in the system, at the center of designing new solutions.”

IV. Beyond Labor & Delivery: Moral Attentiveness in the Postpartum Period

Examining moral inattentiveness in inpatient labor and delivery settings allows us to see the ways in which individual healthcare teams can fail to recognize the needs as patients as needs. However, when thinking about building morally attentive healthcare systems and continued care, the greatest opportunity for improvement lies in the postpartum period.

a. An Account of Moral Attentiveness in the Postpartum Period

The postpartum period is the period in which the majority of preventable pregnancy-associated deaths occur and is often a period in which even patients who received constant care during pregnancy find themselves with significantly less support, despite now being responsible
for a new life. In order to support the flourishing of these new families, we need to develop more robust, attentive systems of care during the postpartum period.

One fundamental strategy in providing more attentive postpartum care and an orienting concern around which to structure postpartum support is to meet families where they are. This phrase can be taken literally, in that more options for in-home support, such as home visiting programs and postpartum doulas could provide low-barrier access to support for families. However this phrase can also be interpreted as an orientation to holding new families in supportive care. Many families are overwhelmed with new responsibilities, potential health needs of new moms and babies, and strong emotions following the birth of a child. By reducing the number of different appointments in different places and providing—for example—integrated health visits for mom and baby where postpartum individuals can be seen in the same location during a consecutive appointment with their child, can increase the likelihood of appointment attendance for maternal visits while also providing an opportunity for questions and needs of both parts of the dyad to be answered in one space.

Peer support and education groups have also been shown to be key supports for new families, with some models grouping parents in close geographic location and with similar due dates together prenatally to receive education and then continuing as a group in the postpartum period, providing both a supportive peer group in which to learn, but also a built-in community within ones neighborhood that can lead to other types of support, such as reciprocal childcare, food trains, and play dates. The support of community-based organizations through food delivery, parenting and support classes, peer counseling, childcare and transportation support should be expanded and more fairly funded as the vital support that it is. And there should be a voluntary space (or living document) in which the services that families are receiving are
contained, that all parties involved can access and reference with families’ consent. This would allow not only for more robust forms of support outside of formal healthcare settings in the ways just described, but could also enable better coordination of these forms of care and enable more collaboration between different services families are receiving.

Moreover, truly attentive care in the postpartum period would require more explicit requirements for employers to provide adequate paid parental leave for new parents so that there is adequate time to adjust to a new life and everything that comes with it. More supportive legislation to provide protection for new families from food insecurity, housing insecurity, and financial burden should be enacted to help lessen social and economic stressors that can exacerbate and create poor health conditions. And access to existing programs to support new families such as WIC should be expanded while also eliminating existing unnecessary barriers to enrolling in these programs and accessing benefits.

The health of new parents and babies is greatly impacted by the communities in which they live, and their health in turn has a great impact on their community. In order to provide more attentive care in the postpartum period, there must be coordinated support across social, economic, communal, medical and political planes in order to ensure that new parents have access to any support they required and that babies are provided a solid foundation through which to grow. A potential manner through which communities could begin to coordinate their efforts is through a responsibilities map, as outlined by Margaret Urban Walker, wherein representatives from all involved stakeholder groups collaboratively map out specific responsibilities that each party has in relation to a vulnerable group and take responsibility for their assigned duties and are held accountable to those duties by the other members of the group. Regardless of whether or not this specific strategy is adopted, there must be a
community-wide system of care that is driven by the voices and needs of new parents that sees their vulnerability as they nurture new life and holds them in their new beginnings.

b. The Role of Healthcare Providers and Organizations in Supporting Postpartum Individuals and Families

As was explored previously in this chapter, the postpartum period can be challenging for parents due to the addition of added stressors (e.g. the addition of a new life that needs to be nurtured and supported, experiences of significant physical and hormonal changes in the birthing parent, sleep deprivation, etc.) that coincide with a withdrawal of support from healthcare teams. One of the reasons that warning signs and symptoms can be missed in postpartum patients is that these patients’ interactions with healthcare providers become limited, and insurers typically only provide reimbursement for 1-2 postpartum visits.\(^{324}\) For postpartum individuals who do not have familial or community support in particular, this can be a devastating and isolating experience.

Among the recommendations that ACOG has offered regarding optimizing postpartum care, the following selection of recommendations support a more robust, relational postpartum care experience:

- “Postpartum care should be an ongoing process, rather than a single encounter, with services and support tailored to each woman’s individual needs
- Anticipatory guidance should begin during pregnancy with development of a postpartum care plan that addresses the transition to parenthood and well-woman care.
- Prenatal discussion should include the woman’s reproductive life plans, including desire for and timing of any future pregnancies. A woman’s future pregnancy intentions provide a context for shared decision-making contraceptive options.
• The timing of postpartum visits should be individualized and woman centered...[and]
should include a full assessment of physical, social, and psychological well-being.325

These recommendations reflect an approach to postpartum care that begins during pregnancy
(and sometime even prior to pregnancy in the preconception period), establishes a relationship
between provider and patient that is ongoing and individualized, and explicitly links the patient’s
current pregnancy to her overall goals and dreams for her life by contextualizing her experience
in the future desires for more children, no more children, etc.

This ongoing relationship that extends into the postpartum period can strengthen
providers’ ability to be morally attentive because it provides more opportunities for the provider
to listen to and get to know their patient, which, in turn, will allow them to communicate more
effectively, notice changes in behavior or demeanor, and build trust. In order for this type of
ongoing provider relationship to exist, however, healthcare organizations must provide space in
care teams’ schedules to accommodate for more appointments in the postpartum period and
health insurers must provide reimbursement for these additional visits. The role of insurers and
reimbursement strategy will be discussed more in depth in Chapter 5 of this dissertation, but for
the current discussion, it is sufficient to note that reimbursement is a crucial element in providing
the structure and foundation that would allow for these more robust, ongoing relationships to
exist.

V. The Role of Community-Based Organizations in Promoting Moral Attentiveness in the
Perinatal Period

Improving healthcare workers’ capacity to recognize the needs of their patients as needs
and provide just, morally attentive care is necessary work. However, it is equally necessary to
draw upon the skills, knowledge and existing relationships of community-based organizations in the fight to provide supportive, effective postpartum care.

**a. The Necessity of Community Partnerships in Providing Morally Attentive Care**

Due to the history of medical racism and reproductive coercion and forced sterilization of women of color by healthcare providers, as well as the attitudes and biases of individual healthcare staff, many patients do not access necessary medical care for fear of the way they and their baby might be treated.\(^{326}\) Moreover, political and economic policies such as redlining and social determinants of health such as lack of access to ongoing transportation have created many communities in which access to medical care is limited.\(^{327}\) For many pregnant and postpartum individuals, there is not adequate access to any medical care, and often even if there is access to medical care, it is not quality care.\(^{328}\)

In response to these factors, resilient communities have established and maintained community-based resources to help support families. Birthing centers, perinatal community healthworkers and doulas, and community-based services such as peer support groups all provide care, support and resources to pregnant and postpartum individuals and their families, particularly in areas in which access to quality medical care is limited. In situations where access to adequate medical care is more prevalent, community-based resources often provide essential support that falls outside of the realm of strictly medical care but supports the social determinants of health such as providing families with diapers, transportation to and from errands, food, and social support via mom-to-mom support groups.\(^{329}\)
b. The Role of Health Plans in Empowering Community Partnerships: A Way Forward

As established in the previous section of this chapter, community-based organizations and community-based practitioners such as doulas and perinatal community health workers can provide ongoing wrap around support through trusted relationships during the perinatal period and well into the postpartum period. This support can not only help to reduce maternal mortality and severe maternal morbidity rates (as well as associated racial and ethnic disparities) but can also contribute to overall improved health outcomes for the mother-baby dyad. Community-based organizations and practitioners have been providing their services to their communities despite uncertain and inconsistent funding and under-funding of their efforts. In fact, many community-based employees who support maternal and infant health themselves suffer poverty and have to work multiple jobs to support their own families due to the lack of material resources that their services are provided by funders and their commitment to keeping the cost of their services low in order to support all families who need care, including those with a low socio-economic status. The lack of adequate compensation for community-based organizations and community health workers is perpetuated by funding structures in which community-facing positions are often positions in which, “the pay is low, and [employees are] typically employed via short-term, grant-funded positions.” This results in an environment in which there is high staff turnover, which is a barrier to providing longer-term, continuous caring relationships, and also places community-based workers in an unfair dilemma in which they cannot remain in their community-centered roles while also being able to provide for the material needs of themselves and their own families. Moreover, the lack of funding and prevalence of need for services often result in community-based workers having unreasonably large caseloads that do not allow...
them to fully tend to the needs of clients due to their being overburdened, which leads to less effective services and higher instances of burnout.\textsuperscript{334}

Financial barriers, lack of communication between and coordination among community-based resources, outpatient clinics, and hospitals, and persistent gaps in resources for social determinants of health needs such as housing and consistent, reliable transportation continue to act as a barrier to community-based resources successfully supporting postpartum families to their full potential.\textsuperscript{335} Due to their impact on both maternal and infant health outcomes, these services need to be fairly compensated as the vital care that they provide in supporting the health of individuals, families, and communities. Health plans are in a unique position to both provide funding for the work of community-based organizations as well as aide the coordination between entities that provide care, due to the influence that reimbursement policies exert over healthcare organizations and individual providers.\textsuperscript{336}

\textbf{Conclusion}

In order to move towards more just, attentive healthcare practitioners and healthcare communities, we need to find ways to be present with and listen to each other as full, multi-dimensional humans in relationship. If our model of relationships in healthcare continue to focus on a closed, prejudiced conception of listening, wherein patients and families are viewed through a set of potential diagnostic and treatment criteria only and are not met in their full humanity, moral inattentiveness will continue to present a major barrier to entering the caring process. Healthcare organizations, teams, and individuals must work together to build the capacity to understand themselves, their colleagues, and their patients as multi-dimensional, complex individuals if the potential for dignity-enhancing care is to be actualized. By centering an anti-
racist, community and family-based approach and by adequately funding those efforts, we can make steps to build just, morally attentive healthcare communities.
Chapter 4: To Whom Are We Responsible? Expanding Networks of Safe Care

We are responsible for the world in which we find ourselves, if only because we are the only sentient force which can change it.

- James Baldwin

4a. The Role of Healthcare Organizations in Supporting Safety: Lessons from Labor and Delivery

This chapter will consider the responsibilities that healthcare organizations have in supporting safety, with a focus on maternal health, through examining the current ways in which failure to accept responsibility has resulted in harm to patients and healthcare staff alike, as well as potential strides towards more responsible care. It will then explore the potential roles of Perinatal Quality Collaboratives and the Alliance for Innovation in Maternal Health in creating a structure for implementing statewide networks of care, as well as their current limitations and areas of improvement.

Introduction

In order to understand the responsibility that healthcare organizations have in supporting safety, we must first understand the role that responsibility plays in an ethics of care approach.

I. The Role of Responsibility in an Ethics of Care Approach to Maternal Health

Joan Tronto positions responsibility as the second phase of the caring process and defines it as a kind of “taking care of” the needs of the person for whom you are caring. While this concept might at first seem straightforward in both theory and execution, determining what...
responsibility actually entails, *how* one might be responsible, and *to whom* one is responsible require considerable reflection and analysis.

**a. The Role of Responsibility within an Ethics of Care**

As Chapter Two explored, the first phase of caring requires moral attentiveness—the ability to recognize another’s needs as needs of moral significance and a call to ethical action. According to Tronto, once we have determined that there is a need, “taking care of involves the recognition that one can act to address these unmet needs….Taking care of involves notions of agency and responsibility in the caring process.”338 In order to assume responsibility as a part of the caring process, one must recognize that there is a part that they can play in addressing the unmet needs of the person(s) whose needs are unmet. Similarly to attentiveness, this act of “taking care of” has traditionally not been construed in a neutral or a-political manner. Historically, direct care, “is often constituted socially in a way that makes caring work into the work of the least well off members of society.”339 When looking at employment trends, professions that entail tending to bodily functions or working directly with individuals to care for their corporeal needs are both underpaid and looked down upon and are, in Tronto’s word, “disproportionately occupied by the relatively powerless in society,”: i.e., women, people of color, and other social categories that do not hold the same social prestige of White men, who occupy a privileged social position.340 While direct caring is naturalized and associated with the individuals of lower social standing who occupy these positions in greater numbers, more physically-removed, supervisory type care is commonly associated with White men in particular.341 It is this type of care that Tronto identifies as “taking care of.”
Tronto points out that taking care of is a phase of caring that historically has been attributed to those in positions of social empowerment and uses male doctors as a prime example of this. While nurses, medical assistants, and even patient access representatives provide the majority of the “hands-on” care that patients receive, doctors are typically said to be the ones taking care of or responsible for the care of their patients. This type of responsibility is elevated and given a type of prestige due to its being performed by those with more power. In the words of Tronto: “doctors who are the most prestigious do less tending to daily care work; the greatest prestige for doctors derives from their research status.” The more removed from direct caring work, the more prestige the work of an individual becomes, which reinforces this categorization of direct care as less valuable/worthy of higher compensation, and more intellectual and supervisory work as more valuable and deserving of higher compensation. This dynamic also creates a complex understanding of responsibility when it comes to care in a medical context: while nurses, medical assistants, and other, less prestigious occupations do the majority of the direct caring work to support the health their patients, doctors are seen as the one “taking care of” the patient.

It is important to keep in mind the social and political aspect of how taking care of has traditionally been conceptualized and the ways in which it has reinforced gender, racial, and socioeconomic power structures when we think about the role of responsibility within an ethics of care. Those in power are typically those whom we care about and those who take care of others, while those who are typically disenfranchised are those who typically give “hands-on” care/perform daily care work and are perceived as needing to be the recipients of care due to socially-constructed perceived deficits that require the aide of those in power. These social and political aspects are why Tronto considers responsibility “both central and problematic in an
“ethic of care,” and a concept that must remain flexible in how it is conceived and constantly be evaluated. Responsibility towards others can vary and shift depending on many factors: what role an individual played in contributing to the needs of the person who needs taking care of, what relationship an individual has to the person who needs care, the skills of the person who might take responsibility to care for another, etc.

In the context of healthcare, it is clear that healthcare workers have a responsibility to care for their patients, but what this responsibility entails in the context of maternal health and how it can be thought of in a flexible, productive manner need to be further explored.

b. Failures of Responsibility: Lessons from the Birth Place Lab

Childbirth is an excellent situation in which to examine responsibility because it presents a situation in which an individual presents to healthcare teams with a clear need (i.e. the child needs to move from its mother’s body to the external world) that the individuals and teams involved have training and experience to respond to (i.e. providers and nurses on labor and delivery floors have specific education, training and experience in supporting individuals in labor and their children). However, childbirth also presents unique considerations and challenges to considering the responsibility of care teams due to the often high-stress and unpredictable nature of the process of giving birth, the fact that the care team has to consider the health and care of (at least) two patients in tandem, and the participatory nature of the process.

The Birth Place Lab, founded in 2011, is situated in the Division of Midwifery at the University of British Columbia, and specializes in community-based research within the realm of maternal health. The lab’s research focuses on four domains of collective action: “(1) person-centered measurement of equity, quality, and safety; (2) designing and implementing
accountability tools and systems; (3) improving health professional education on anti-oppression, anti-racism, and cultural safety; and (4) expanding representation in the perinatal research and clinical workforce. In 2019, The Birth Place Lab conducted a study to evaluate the qualitative experiences of individuals giving birth in the United States. Through this study, researchers found that 1 in 6 women experienced a form of mistreatment by their providers during childbirth. Mistreatment in the context of this study entailed any of the following: being shouted at or scolded by providers, “health care providers ignoring women, refusing their request for help, or failing to respond to requests for help in a reasonable amount of time”, “violation of physical privacy” and “health care providers threatening to withhold treatment or forcing them to accept treatment they did not want.” The rate at which patients experienced these types of mistreatment was substantially higher for women of color, those who gave birth in a hospital, patients with low socio-economic status, and those who experienced health complications and/or unexpected events in the birthing process. The highest rates of mistreatment were reported in patients who questioned or voiced disagreement with a health care provider’s recommendation for care for themselves or their children.

The revelation of this mistreatment is striking not only because of its prevalence and associated inequities, but also due to the nature of the mistreatment. Mistreatment from providers has been directly linked to patients’ experiences of birth trauma and has been recognized as a contributing factor to postpartum mental health conditions as well as longer term conditions such as PTSD, fear of giving birth in the future, distorted or negative body image, and “feelings of dehumanization.” Experiences of mistreatment can also lead patients to fear receiving medical care or not seek needed health care in the future. When considering this type of provider mistreatment, the Birth Place Lab team highlights four common themes from an earlier analysis.
of patients’ experiences of provider mistreatment: “‘prioritizing the care provider’s agenda’; ‘disregarding embodied knowledge’; ‘lies and threats’; and ‘violation’.”354

The type of mistreatment perpetrated by providers within the context of this study displays a failure of responsibility on the part of providers in several ways. In instances of physical and verbal abuse, providers displayed a failure of responsibility in their refusal to listen to and respond to the needs of their patient while exerting force over their patient. For example, when a patient asks for clarification on why a provider is choosing to move forward with a previously undiscussed course of action and the provider not only does not respond to the patient but shouts at or physically redirects the patient, this constitutes a failure of responsibility. The provider has failed to understand his responsibility to take care of his patient through providing her with adequate context and sufficient communication and instead exercises brute force. When providers ignore women’s requests or take an unreasonable amount of time to respond to them, they are failing to be responsible to their patients by not recognizing that the requests they are not responding to or not prioritizing are a part of the care their patients need. When providers threaten or lie to their patients or violate their privacy or boundaries, they are failing their responsibility to their patients by not using their position of power to protect them. If a provider lies to, threatens, violates or abuses his patient, he has failed his responsibility to care for that patient.

In light of the findings of the Birth Lab’s study, healthcare organizations have a twofold duty in improving the treatment of women during childbirth: a) providing support for providers whose maladaptive behavior is a result of unresolved trauma incurred while on the job and; b) implementing standardized approaches to assessing respect for patients and patient autonomy in the birth process.355 356
II. Who Is Responsible?

Given the ways in which social and political factors have historically and contemporarily shaped conceptions of responsibility as well as individual and collective actions, it is important to understand the ways in which structural factors such as obstetric racism impact our views on responsibility and our response to harm caused by failures of responsibility.

a. Obstetric Racism and the Question of Responsibility

When considering the steep and persistent disparate health outcomes for Black mothers and infants in the United States, Black feminist scholars have highlighted that health inequities are not the result of racial differences but of racism. In order to more fully understand the specific ways in which racism is a determining factor in how Black mothers and children are conceived of and treated and through almost a decade of research, interviews, and community outreach, Dána-Ain Davis coined the term obstetric racism. Obstetric racism “highlights the forms of violence and abuse that medical personnel—and potentially any personnel within medical institutions—routinely perpetuate against Black women…[and] is composed of beliefs and practices that harm the reproducing Black body.” This routine violence and abuse is because “woven into the practice of reproductive gynecological, and obstetric services are the historical ways that Black women and their bodies have been both valued for their experimental and capitalist potential as well as derided for wiliness and unruliness.” Obstetrics as a field arose out of and was shaped by racist practices and racial hierarchies that were at the time seen as scientific and biological truths. In a social and political context in which those racial hierarchies still exist, “racial hierarchies have led to differential practices, tasks and clinical decisions.”
Obstetric racism provides a conceptual framework through which to understand the experiences that Black families encounter when attempting to receive medical care. The existence of obstetric racism also raises many questions and concerns when considering responsibility within a dignity-enhancing ethics of care approach to maternal health. When providers are providing care within a context that has been inherently shaped by racism, there arises a responsibility to respond to the need to dismantle and overturn the conditions that create unjust care for many of their patients. As with many social factors that have significant impact on the health of their patients, healthcare workers may not have the power to completely control or eradicate detrimental factors, but they do have a responsibility to understand the ways in which they might be contributing to those factors and the role they can play in mitigating those factors and to subsequently act accordingly.

b. Harm and Responsibility

Section I of this chapter explored the responsibility that healthcare workers have to appropriately respond to the needs that their patient articulates during the childbirth process. However, when considering mistreatment, obstetric racism, and the current state of healthcare in the United States, a consideration of responsibility must also include an examination of harm and responsibility in the face of having harmed patients or witnessed patients being harmed. This section will consider both the responsibility of healthcare workers to respond when they have caused their patient harm and the responsibility to respond when they witness harm being inflicted.

In considering harm in the context of medicine, Nancy Berlinger has noted that approaches to this topic have often focused on the ubiquity of harm (i.e. “to err is human”) and
the legal and social ramifications of harm, but not on the question of forgiveness, and by extension, the process that should be undergone in order to strive towards forgiveness and the fulfillment of the obligations one owes those whom they have harmed. In shifting the focus from medical error to a framework of medical forgiveness, Berlinger suggests that three steps are necessary to move towards forgiveness after harm has occurred: disclosure, apology, and repentance.

Berlinger notes that disclosure, “continues to be among the most highly contested and emotionally fraught issues within conversations on patient safety in the United States.” While in general there is an understanding that healthcare professionals have a duty to be honest with their patients, when it comes to individual providers and complex situations, the mandate to tell the truth becomes more complicated for reasons that are largely rooted in ego and in fear: “If I disclose an error, the patient will sue me, ergo, I will not disclose errors.” This lack of willingness to disclose the truth when an error occurs has serious effects on patients. Berlinger notes, “A patient who is injured in the course of caregiving suffers twice; this patient is doubly vulnerable within the institution, whose culture perceives this patient as a potential legal adversary, a ‘risk’ to be ‘managed.’” In a cultural context in which legal liability, professional prestige, and professional competition all incentivize non-disclosure of harm, Berlinger draws upon Bonhoeffer to argue that providers have an obligation to look beyond the perspective of their own suffering to the suffering of the patient in order to realize the true impact of both his actions and his non-disclosure. “As long as he cannot admit that he is not the sole or principle victim of this incident due to its perceived impact on his career, income, or self-image; as long as he fears what the injured patient might do to him rather than recognizing disclosure as part of the
narrative of caregiving, he will not be able to understand and embrace full disclosure as an ethical norm.”

If we support our organizational cultures in normalizing disclosure after harm has been committed, we must also then create environments in which providers can deliver true apologies, i.e., “an expression of responsibility, an apology for an event in which the speaker was intimately involved,” rather than an expression of sympathy for the fact that an event occurred. In recognition of the importance of apologies after harm has occurred, several states including Oregon and Colorado have enacted “I’m sorry” laws that provide legal protection for providers who apologize after harm has occurred. These laws do not entail that lawsuits cannot be brought against providers who have harmed patients, but, rather, that the apology itself cannot be used as evidence of culpability in a legal case, thereby encouraging and allowing for apologies in the context of the provider-patient relationship that are protected from legal systems. Berlinger notes, however, that while apologies are necessary in the context of responding to harm, there is also a need for action to demonstrate responsibility for the harm that was caused: “apology, the actions that acknowledge harm, responsibility, and regret, and repentance, the actions that materially restore the injured person to health, that repair the relational breach, and that safeguard against future injuries, are not at all the same thing.” Physicians should feel able and morally obligated to apologize to patients or patient families after they have caused them harm, but this is not enough; if there is to be apology taken in its full sense of responsibility, there must also be action on the organizational level to ensure that the patient or family is compensated, that policies are changed, or that the situational factors that led to harm have been addressed. Repentance in this context can entail compensation for patients and families, but more than anything it entails, in Berlinger’s words, “giving the pen back” to those who have been harmed;
i.e. allowing those harmed to be a part of the process in determining what follow-up actions to
the apology issued would illustrate taking responsibility for the harm inflicted and assurance that
there was less likelihood that this harm would be inflicted upon others in the future.372

Our current, reactive, risk-management and liability-focused approach to medical harm
has negative consequences for patients, families, and healthcare providers alike, because it does
not support the disclosure of recognition of having caused harm, and therefore does not support
the potential for healing of relationships between providers and families or taking responsibility
for the harm one has caused. In order to move towards a context in which providers can take
responsibility for their actions and to give patients and families the chance to receive the
apologies and reparations they deserve, more honest, responsible responses to harm need to be
supported on the organizational level.

III. To Whom Are We Responsible?

Now that we have illustrated failures in responsibility and the responsibility that
healthcare workers and institutions have to prevent and respond to harm their patients experience
during the birthing process, we can now turn to ways in which organizations can promote
standards of care and cultures of respect.

a. Respect and Autonomy During the Birthing Process

In an attempt to help guide efforts to support Black pregnant and postpartum women, the
article “The Ethics of Perinatal Care for Black Women: Dismantling the Structural Racism in
‘Mother Blame’ Narratives” by Karen Scott et al. draws upon the 8 ethical standards advocated
for by the Black Mamas Matter Alliance (BMMA). BMMA defines itself as, “a Black women-
led cross-sectoral alliance that centers Black mamas and birthing people to advocate, drive research, build power, and shift culture for Black maternal health, rights, and justice.”373 Their work aims to influence change on the level of policy, to further research and research methods to provide evidence basis to inform policy recommendations, to promote better care for Black parents, and to restructure current conversations in maternal health to center the needs and voices of Black parents.374 From this overarching viewpoint, they have posited the following ethical standards: “1) Listen to black women; 2) Recognize the historical experiences and expertise of black women and families; 3) Provide care through a reproductive justice framework; 4) Disentangle care practices from the racist beliefs in modern medicine; 5) Replace white supremacy and patriarchy with a new care model; 6) Empower all patients with health literacy and autonomy; 7) Empower and invest in paraprofessionals; and 8) Recognize that access does not equal quality care.”375 These ethical standards align with a rights-based dignity enhancing approach to care, and center respect and autonomy as two central ethical components of good, quality care.376

In order to make necessary changes to organizational practices and support respectful, equitable care, it is important that healthcare teams put in place mechanisms to receive honest, ongoing feedback about the experiences of their patients while in their care.377 Two tools developed by the Birth Place Lab can provide a structured, actionable way to obtain this qualitative feedback: The Mother’s Autonomy in Decision Making (MADM) scale and the Mothers on Respect Index (MOR). The MADM scale is an instrument that was developed through a patient-led process and asks the patient to rank the following statements on a scale of Completely Disagree to Completely Agree:

- “My provider asked me how involved in decision making I wanted to be
• My provider told me that there are different options for my maternity care
• My provider explained the advantages and disadvantages of the maternity care options
• My provider helped me understand all the information
• I was given enough time to thoroughly consider the different maternity care options
• I was able to choose what I considered to be the best care options
• My provider respected that choice

This tool should ideally be coupled with and asked in conjunction to the Mothers on Respect Index (MOR) and will therefore be discussed together.

The MOR scale contains the following items, to which the patient answers Yes or No:

“Overall while making decisions during my pregnancy I felt:
1 Comfortable asking questions
2 Comfortable declining care that was offered
3 Comfortable accepting the options for care that my (midwife, doctor) recommended
4 Pushed into accepting the options my (midwife, doctor) suggested (reverse scored)
5 I chose the care options that I received
6 My personal preferences were respected
7 My cultural preferences were respected

During a prenatal visit I held back from questions or discussing my concerns:
8 Because my (midwife, doctor) seemed rushed (reverse scored)
9 Because I wanted maternity care that differed from what my (midwife, doctor) recommended (reverse scored)
10 Because I thought my (midwife, doctor) might think I was being difficult (reverse scored)

When I had my baby I felt that I was treated poorly by my (midwife, doctor):
11 Because of my race, ethnicity, cultural background or language (reverse scored)
12 Because of my sexual orientation and/or gender identity (reverse scored)
13 Because of my health insurance (reverse scored)
14 Because of a difference in opinion with my caregivers about the right care for myself or my baby (reverse scored)
The tool is meant to measure aspects of provider-patient communication and experiences within the birthing process, with the MOR index focusing on three domains: “1. A women’s sense of autonomy and comfort when accepting or declining care options, 2. Evidence of the woman modifying her behavior as a result of fear of anticipated disrespect, and 3. Perceived differential treatment as a result of a non-modifiable sociodemographic factor.”

Questions 1-7 relate to the first domain, questions 8-10 relate to the second domain, and questions 11-14 relate to the third domain. Questions 4, 8, 9, 10, 11, 12, 13, and 14 are all reverse scored, which means that if the patient answers in the affirmative to these questions, the score for these answers will be lower. This allows the overall experience to be totaled as a singular score that would reflect the extent to which care was experienced as respectful or disrespectful. For example, if a patient answered “Yes” to question 1, that would receive a score of 1, as that indicates an experience of respect and comfort in communicating with one’s provider. If a patient answered “Yes” to question 4, however, this would receive a score of 0, as answering in the affirmative to feeling coerced by one’s provider indicates an experience of mistreatment. A higher score on the scale indicates that a patient experienced her care as more respectful, with scores of 7 or higher considered as being indicative of respectful care. However, the breakdown of the questions into the three domains also allows for more nuance in understanding the qualitative dimensions of the experience, and the scale’s creators recommend that each of the three dimensions are considered individually when considering patients’ experiences of their care as respectful or disrespectful. For example, if a patient’s score for the first two domains indicates that they experienced their care as disrespectful, the questions pertaining perceptions of differential treatment can give a sense of what factors the patient believes may have contributed to this treatment. Moreover, by focusing the index on patient perception of care, the Birth Place lab tools also allow for a conversation
about the experience itself, rather than the specific health outcomes that otherwise might be the only topic of discussion when considering quality of care. These tools support the standards for ethical care by providing patients the opportunity to indicate the extent to which their experience of their pregnancy and childbirth felt empowered or was diminished through disrespectful communication and actions or communication and action that limited their ability to exercise their right to autonomy.

These tools also help shape a picture of what respectful care should look like by asking directly about whether or not desired elements of care were included; this includes being asked by providers how involved in the decision-making process an individual wants to be, ensuring that providers have discussed different options for care with patients, and determining that the patient has understood those options before choosing. This includes not only an emphasis of respect for autonomy, but an understanding of the integral role that relationship plays in ensuring/promoting a patient’s ability to make choices for herself. Patients are the experts of their experience, but they rely upon medical providers to equip them with the knowledge around medical best practices for the condition they are experiencing. By assessing the extent to which the experience with one’s provider allowed one to feel respected and capable of making an informed choice about their care, the tools illustrate the foundational role that the patient-provider relationship plays in ensuring respect and patient autonomy.

b. Beyond Patient Safety

Implementing tools to measure patients’ experiences of care and the extent to which that care is respectful and promoting of patient autonomy are invaluable in the process of helping healthcare workers understand their role in improving care for patients and taking responsibility.
However, to fully address the question of responsibility and safety, we must think beyond merely patient safety and consider the safety of healthcare providers and care teams as well. In Committee Opinion No. 825: Caring for Patients Who Have Experienced Trauma, ACOG acknowledges in one of its key recommendations that “obstetrician-gynecologists should create a safe physical and emotional environment for patients and staff” (my emphasis added).\textsuperscript{381} Despite including this in their recommendations, further guidance on what this safety for staff might entail is vague and limited, noting only that staff and clinicians may also be survivors of trauma or may experience secondary trauma and that “it is important that clinicians and staff learn to care for themselves, both in the moment and in the long term. Caregivers need to learn to balance maintaining compassion and empathy while not over-identifying or re-living patient experiences. It is important to learn the signs of professional burnout and to prioritize good self-care. It is also essential for the clinical environment to have supportive policies and practices that prioritize staff well-being.”\textsuperscript{382}

As we discussed in Chapter Two, many of the discussions around healthcare staff safety have missed the mark because they focus on the potential physical threat that patients might cause to staff. This has led to an approach in which staffing numbers and shift times, as well as strategies such as de-escalation communication are the focus of interventions to improve the culture of safety in in-patient settings. However, recent attempts to consider the environments in which staff work and the effect that the physical and cultural environment might play in promoting the mental health and wellbeing of healthcare professionals have found that, “self-motivation and well-being within a given domain are largely dependent on opportunities for the satisfaction of basic psychological needs for autonomy, competence, and relatedness….when context provides opportunities to experience autonomy (i.e., volition, voice and initiative),
*competence* (effectiveness and optimal challenges), and *relatedness* (connectedness and belonging), people are predicted to demonstrate greater self-motivation and adjustment."383 This approach, which is grounded in Self-Determination Theory (SDT) is vital to understanding ways in which overall cultures of safety can be built because it considers not only health or career outcomes, but the specific elements of “institutional climate, including management styles, reward contingencies, and the level of challenges and demands,” all contribute to or diminish workers’ abilities to flourish in their environment and in relationship with others.384

SDT is also a helpful theory to discuss within an ethics of care approach, as it highlights the delicate balance between individual autonomy and freedom to make choices about one’s work with the equally-vital importance of relationships in ensuring that workers feel supported and capable of doing their job well.385 Staff that work in environments that support their ability to be informed, competent individuals while also providing opportunities for developing and cultivating healthy peer and mentor relationships have been shown to be more effective in their work with patients, less fearful of their patients, less controlling of patient behavior, and more satisfied with their job overall.386 As we will see in Section IV, experiences of unresolved trauma in healthcare workers present a threat to not only the wellbeing of the individual employees themselves, but a risk to patients and families as well. Healthcare organizations have a responsibility to provide working conditions that support the autonomy, competence and relatedness of their employees. By providing those conditions, they will not only be fulfilling their obligation to protect and support the personal and professional development of their staff, but they will be supporting the health of their patients as well.
IV. Examining the Role of Secondary Trauma in Disrespectful Care

The trauma that healthcare workers experience through their profession can be difficult to identify and address at times because of the ways in which traumatization, compassion fatigue and burnout can present themselves behaviorally. While steps have been made to begin to understand the needs of healthcare workers who have experienced trauma at work, there is growing research to suggest that one of the ways in which unresolved trauma and secondary trauma may present itself is through behaviors that were identified in the types of mistreatment identified in the first sections of this chapter: “verbal and physical abuse…discrimination, failure to meet professional standards of care, poor rapport.”

a. The Consequences of Provider Secondary Trauma in Labor & Delivery

Research has illustrated that exposure to traumatic events is an elevated risk factor for compassion fatigue in healthcare workers. Compassion fatigue is typically thought to be compromised of two elements: burnout and secondary traumatic stress. Burnout can be defined as a process that entails three dimensions: “emotional exhaustion, depersonalization, and lack of professional efficacy.” When unaddressed, burnout can increase in intensity over time and can result in physiological and emotion symptoms that impair individuals’ ability to perform their job adequately, negatively impact workers’ sense of self, and mimic many of the symptoms of depression. Secondary traumatic stress can be defined as stress “resulting from knowledge about a traumatizing event experience by a significant other” and “from helping or wanting to help that other.” Symptoms of secondary trauma are usually linked to a specific experience and can mimic those of Post-Traumatic Stress Disorder and well as feelings of helplessness, confusion, and social isolation.
Healthcare workers working on Labor and Delivery units are at elevated risk for experiencing compassion fatigue due to the unpredictable nature of process of childbirth, shifts that last for long hours without the opportunity for potentially needed breaks, and the fact that when adverse events do occur, they can be experienced as inherently traumatic due to the particular patients involved. For example, healthcare workers might be emotionally distressed and saddened by the death of an elderly patient in their care but this event would most likely not typically be experienced as traumatic; when a mother or child dies in the process of childbirth, or there is an adverse event that entails the death of either mother or child as a viable potential, this can often be experienced as traumatic due to the youth and unlived potential of both of these patients. As a midwife once told me: “there is something haunting and unnatural about deaths that occur during childbirth. People just aren’t supposed to die this way.” This sentiment has also been supported by qualitative research indicating high rates of secondary traumatic stress, compassion fatigue, and higher rates of burnout in midwives who participate in traumatic birth events.

When thinking about compassion fatigue and the behavior that healthcare workers can exhibit towards patients, the following symptoms are important to note: “Lack of empathy/sympathy, Irritability/anger, Hyper-arousal, Intrusive thoughts, Anxiety, Trepidation of working with some patients.” These symptoms can result in behaviors from healthcare workers that were categorized as mistreatment in the Birth Place Lab’s Mistreatment by Care Providers in Childbirth Indicators. Behaviors such as physically-coercing patients may at time arise from experiences of hyper-arousal or anxiety when a patient or their situation invokes a previous clinical experience that had a negative outcome. Instances of providers yelling at
patients or verbally scolding them could be the result of anxiety, hyper-arousal, or intrusive thoughts.

As Bessel van der Kolk has emphasized, even if we do not consciously link past traumatic experiences to the current experiences that may trigger trauma responses in us, our bodies keep the memory of these experiences within them and will act on instinct unless if the body’s memory is tended to and resolved. Van der Kolk explains: “if you are not aware of what your body needs, you can’t take care of it. If you don’t feel hunger, you can’t nourish yourself. If you mistake anxiety for hunger, you might eat too much. And if you can’t feel when you’re satiated, you’ll keep eating….the moment-to-moment shifts in our inner sensory world…carry the essence of the organism’s responses: the emotional states that are imprinted in the body’s chemical profile, in the viscera, in the contraction of the striated muscles of the face, throat, trunk, and limbs.” Even if members of care teams are aware that they are experiencing some of the symptoms that can arise through experiencing trauma, they might not make the connection that those experiences are the result of trauma. Moreover, in the hospital setting, individuals might even be incentivized to not consider that certain behaviors and feelings are the result of trauma, due to a cultural environment that encourages employees to “push through” difficult experiences and brush off negative feelings that might arise.

In order to understand more fully the role that experiences of trauma during births and experiences of secondary trauma might be contributing to behaviors that result in the mistreatment and traumatization of patients giving birth, we must help healthcare staff understand that the symptoms and behaviors they are exhibiting might be the result of trauma and then work with them to address and resolve their experiences so that they will be able to better support their patients as well as lead happier and healthier lives.
b. The Responsibility of Healthcare Organizations to Respond to the Secondary Trauma of Healthcare Providers

As was illustrated in the previous section, secondary trauma, burnout, and compassion fatigue can have negative consequences not only for healthcare workers’ mental health, job performance, and overall professional quality of life, but can also directly impact the way in which they interact with their patients and result in mistreatment of fellow coworkers and patients. While more research needs to be done specifically on the ways in which secondary trauma, burnout and compassion fatigue can result in patient mistreatment in the context of maternal health specifically, the extensive research that has been conducted about compassion fatigue, burnout, and secondary traumatic stress has illustrated that structural factors and organizational factors play a large role in determining both the onset of these conditions and their worsening or lessening over time.402

John A Gallagher and Jerry Goodstein have argued that at its core, organizational ethics has three fundamental topics of concern: integrity, responsibility, and choice.403 Organizations must ensure that the integrity of their institution is maintained through policies and environments that reflect the values espoused in their mission statements that were crafted to reflect core organizational values.404 Organizations also have a duty of responsibility to multiple stakeholders involved in their day-to-day operations as well as the sustained cultures and systems of care that operate under their guidance.405 When it comes to choice, organizations have the responsibility to identify “core responsibilities” within the context of their organization in a manner that supports and maintains the organization’s institutional integrity.406 In short, organizations have an ethical duty to, “identify the structures, processes and policies that support choices that are made in a reflective and responsive manner,” and that are responsive to the
needs and values of the communities they serve and of which they are a part. Organizations should design their missions in response to the needs of their communities, and the mission they determine should be the orienting force around which the rest of their structures and systems are developed.

With this view of organizational ethics in mind, it is clear that organizations have a responsibility to respond to the traumatic experiences and secondary trauma of their employees, both because the behavior of their employees could pose a threat to patient care and patient experience but also because the health and wellbeing of employees is a central component of maintaining the integrity of their institution and of fulfilling their responsibility towards their employees (i.e. one of their primary stakeholders).

When organizations do not tend to the mental health and wellbeing of their employees—particularly when the health condition in question is a result of the work employees perform as a part of their role in the hospital—they do not fulfill their responsibility to their missions to promote health in individuals and especially in their community, and they not only do relieve suffering, but they enable and add to suffering that is already occurring. If an organization claims to care about and promote health, they need to have policies and procedures to respond to experiences of trauma their employees might undergo during the course of their employment at the hospital. Failing to do so poses a serious threat to their institutional integrity and constitutes a failure of responsibility, as well as poor modeling of good decision making for their employees and overall community.
V. The Alliance for Innovation in Maternal Health: Building an Infrastructure for Responsibility?

As more attention has been paid nationally to the necessity of improving care and health outcomes for pregnant and postpartum individuals, the desire to create uniform standards of care and resources to help hospitals implement best practices surrounding those standards of care has grown as well. The Alliance for Innovation in Maternal Health (AIM) is arguably the largest effort nationally to set, maintain and spread consistent standards of care across hospitals in the United States.

a. The Alliance for Innovation in Maternal Health (AIM) and the Role of Patient Safety Bundles in Building Hospital Infrastructure for Responsibility

AIM was created in response to the rise in maternal mortality rates and considers itself a “national partnership of provider, public health and advisor organizations” that “provides evidence-based, front line resources for birth facilities and provider/public health teams to adapt and implement a series of action steps or ‘bundles’ on high risk maternal conditions.” With its first cycle of funding announced in spring 2014, AIM developed and worked with select states to roll out patient safety bundles around 3 contributors of poor maternal outcomes that had been identified as both significant and preventable with early intervention: postpartum hemorrhage, severe hypertension, and venous thromboembolism (VTE). Patient safety bundles contain key interventions and best practices that hospital teams can work to implement via quality improvement initiatives. The patient safety bundles are structured around Readiness, Recognition & Prevention, Response, Reporting/Systems Learning, and as of 2022, Respectful, Equitable and Supportive Care.
The AIM Patient Safety Bundles can be adopted by individual hospitals, but efforts to adopt and implement the patient safety bundles across individual states have been driven by statewide Perinatal Quality Collaboratives (PQCs), which will be discussed in further detail in Section B of this chapter. The benefit of having a coordinated statewide effort to adopt the Patient Safety Bundles is that it promotes the adoption of a more unified standard of care across an entire state, which will hopefully reduce variability in the standard of care at the individual hospital level. A statewide effort also allows for more peer-to-peer collaboration, sharing of resources, and designated time and funds to providing additional support in adopting established best practices in an accelerated timeframe. There are many changes that need to be made to improve the care that individuals receive in the perinatal period, and a coordinated effort at the state level certainly supports those efforts. However, as we will see in following sections of this chapter, the hospital-centric model of the AIM patient safety bundles has contributed to an approach in which the entities with the most resources (i.e. hospitals) are given the most support, while the individuals and organizations that have made a substantially larger impact in improving overall health outcomes for this patient population (i.e. community-based organizations and supports such as doulas) are considered only tangentially and without the financial or technical support they deserve and require.

b. Beyond AIM: Limitations of the Patient Safety Bundle Approach to Improving Patient Care

While establishing consistent and robust standards of care nationally is a worthwhile and worthy goal, it is important to understand the limitations of the patient safety bundle approach utilized by AIM. Patient safety bundles provide a set of guidelines and best practices, but these
best practices will never be fully effective if they are not accompanied by robust attempts to promote empathy and caring at a basic, human level. Many of the changes that are required at the individual hospital level to improve care for patients who belong to socially-disempowered groups involve changes in culture, not merely the adoption of a set of protocols. Moreover, patient safety bundles often entail checklists and protocols that serve as a series of levers. For example, in the Obstetric Hemorrhage bundle, there is a requirement that for every hemorrhage there is “a unit-standard, stage-based, obstetric hemorrhage emergency management plan with checklists.” Having a standardized and practiced plan for obstetric hemorrhages is indeed a good and necessary step in reducing deaths and severe maternal morbidity due to hemorrhage, the implementation of the emergency management plan is dependent upon the recognition that a patient is hemorrhaging. If the unit at which care is taking place has not also worked to cultivate a just, attentive unit culture, the distress of patients might not be recognized as indicators that the emergency management plan is needed. To return to the tragic death of Kira Johnson—Cedar Sinai Hospital had already implemented the AIM Obstetric Hemorrhage patient safety bundle at the time of Mrs. Johnson’s death. Patient safety bundles can be effective in saving lives, but only if they are implemented in a compassionate and equitable manner.

Moreover, the patient safety bundles are extremely hospital-centric in their design. While this might at first glance seem to be an obvious and neutral choice, given that they are designed to adopt the QI implementation framework that many hospitals employ, the design of the patient safety bundles for the newer topics of focus in particular gesture at the need for clear clinical pathways and relationships between hospital teams and outpatient and community-based resources but do not provide substantial guidance on how to develop these pathways or their vital importance. For example, the Care for Pregnant and Postpartum People with Substance Use
Disorders Patient Safety Bundle includes elements such as, “Engage appropriate partners to assist pregnant and postpartum people and families in the development of family care plans, starting in the prenatal setting,” and, “Develop and maintain a set of referral resources and communication pathways between obstetric providers, community-based organizations, and state and public health agencies to enhance services and supports for pregnant and postpartum families for social determinants of health needs, behavioral health supports, and SUD treatment.”

While these elements are vital to improving care for this patient population, and while they are welcome additions to the bundle, in a context in which hospitals have not developed or maintained these types of relationships, there needs to be significant guidance and technical assistance in supporting them in doing so. Moreover, despite stating that these entities should be included, the AIM national meetings are still comprised primarily of representatives from individual state PQC's and occasionally state departments of health, and the leadership of AIM state teams are from hospitals and state departments of health, not community-based organizations or outpatient clinics. In order to model and support the multi-disciplinary, cross-contexts-of-care shift that needs to take place in order to see overall health outcomes improve for high-risk patient populations, AIM needs to shift their approach and their practices to more fully embody a collaborative community in which hospitals play a part, but are not the primary focus and locus of improvement efforts.

Conclusion

No one person or institution is responsible for the current state of obstetric racism and inequitable treatment of families of color in this country. However, every healthcare practitioner
and every healthcare institution is responsible for understanding what their role has been in perpetuating and enabling harm and inequitable care and how they can act to disrupt and divest from the systems that have created and continuously produce health inequities. To echo Tronto, taking care of others requires that we understand and exercise agency in our relationship to the unmet needs of those for whom we care.

4b. Perinatal Quality Collaboratives: A Structure for Implementing Statewide Networks of Care?

Introduction

Perinatal Quality Collaboratives present a promising structure for implementing needed improvements in maternal and newborn care, particularly in the context of specific patient populations. However, in order to fully capitalize on the potential that these collaboratives possess, it is essential that the basic structure of the perinatal quality collaborative be expanded to more robustly include all birth settings as well as all participants and stakeholders in the preconception, prenatal, and postpartum period.

I. Perinatal Quality Collaboratives

a. The History of Perinatal Quality Collaboratives

State Perinatal Quality Collaboratives (PQCs) are “state or multistate networks of multidisciplinary teams, working to improve measurable population outcomes for maternal and infant health by advancing evidence-informed clinical practices and processes using quality
improvement (QI) principles. Originally spearheaded by neonatologists and neonatal networks through the Vermont-Oxford Network (VON) in the 1990s, similar efforts arose in states such as California in 2006. Following the California Maternal Quality Care Collaborative’s (CMQCC) success in reducing rates of maternal mortality in their state, other states began adopting the PQC framework at a rapid rate.

Following a Quality Improvement framework, PQCs typically involve structured initiatives around specific areas of improvement or patient populations. Popular maternal health PQC initiatives in the earlier years of these statewide collaboratives included hemorrhage, promoting vaginal birth, treatment of severe hypertension, and smoking cessation. After an initiative topic is selected, PQCs coordinate either the development of or adoption of a pre-existing set of best practices and key interventions to drive improve efforts (adoption of the AIM patient safety bundles for selected topics is a common choice) and then work with hospital teams across their state to develop and implement quality improvement projects at the hospital level to improve health outcomes within the selected topic or patient population.

Because QI is traditionally conducted on the hospital level and is defined by its ability to track measurable, incremental progress, and because the PQCs were developed largely by clinical providers who were concerned with making improvements and setting standards within their clinical setting, the initial topics and quality improvement initiatives of PQCs were comprised of hospital teams that focused on specific clinical best practices surrounding their topic area. In the context of projects such as OB Hemorrhage and the treatment of severe hypertension, this resulted in the creation and implementation of toolkits, resources such as hemorrhage carts that can be on-hand on L&D if a hemorrhage does occur, and simulation drills that help teams prepare in real time for an emergency response. While PQCs have always
stated that the partnership and input of a variety of stakeholders is essential to the development of their initiatives, including public health officials, professional organizations such as ACOG and AWOHNN, and patient and community voices, the scope of the achievable goals for most PQC initiatives have primarily been focused on what can be achieved on the level of hospitals.428

b. Perinatal Quality Collaboratives and the Role of Expanded Networks of Care in Improving Care in the Perinatal Period

While it is essential that hospital teams make improvements to their day to day practices and the care that they provide mothers and babies, in order to see optimal improvement in maternal and child health outcomes, the focus of maternal-child health improvements needs to move beyond that of hospital teams.429 Given that the vast majority of maternal deaths occur in the year following a birth, at minimum, efforts to improve maternal health outcomes need to be extended to all elements involved in the postpartum period. But given the importance of ongoing relationships throughout pregnancy in supporting care in the postpartum period that we discussed in Chapter Two of this dissertation, the scope of these initiatives also needs to include pregnancy and ideally pre-conception care as well.

Moreover, given that patients spend the vast majority of their pregnant and postpartum lives outside of the hospital, the wider network of community-based organizations, peer support networks, and ancillary services need to be areas of focus for improvement as well. The inclusion of these entities also highlights the necessity that the improvement opportunities and goals of PQC initiatives be identified and driven by pregnant and postpartum individuals themselves, and in particular by the patients who have been most effected by the failures of our current systems of care.430 In every healthcare setting it is important to have the individuals who
are most impacted by current limitations in caring processes provide their input on how they are impacted by those limitations and what they view as meaningful markers for "success". As we will see in section II of this chapter, this input is even more essential in trying to improve outpatient systems of care because there are multiple points of contact with different providers and additional requirements on the part of patients in order to access care (i.e. you have to go to multiple appointments, often with multiple providers, across an extended period of time).

The crisis in maternal health certainly points to the necessity of improving the care that individuals receive in hospital settings, but it also points to the need for better coordination of care and unified efforts to improve the overall health of pregnant and postpartum individuals. Hospitals and health systems have an immense amount of resources and time poured into their improvement efforts, but what is needed is the same allocation of time and resources to supporting the other types of care individuals need as a part of their childbirth experience and a robust attempt on the part of hospitals and health systems to understand more fully their role in the overall health and care of individual pregnant people and their communities.

II. Perinatal Quality Collaboratives and the Opioid Crisis

As rates of Opioid Use Disorder (OUD) rose rapidly in the United States, the impact of OUD on pregnant and postpartum individuals and their children quickly became an area of interest for PQC s in states where rates of opioid use and death by overdose are high. However, the work that PQC s have undergone to address the impact of opioid use in the perinatal period highlights both the strengths of the current PQC approach and its clear limitations.
a. The Perinatal Quality Collaborative Approach to the Opioid Crisis

PQCs in many states determine their initiative topics by the findings of their state’s Maternal Mortality Review Committee.\textsuperscript{431} Given the prevalence of Opioid Use Disorder in most states, it is not surprising that death by overdose has risen to the top of many state’s causes of pregnancy associated deaths. Moreover, the identification of Opioid Use Disorder as a public health crisis nationally as meant that additional funding has been given to federal entities and state departments of health to support programming that targets identification of and treatment for pregnant and postpartum individuals with Opioid Use Disorder, with PQCs in Colorado, Delaware, Florida, Georgia, Illinois, Louisiana, Massachusetts, Minnesota, Mississippi, New Jersey, New York, Oregon and Wisconsin all receiving funding from the CDC to launch Opioid projects on both the maternal and newborn levels.\textsuperscript{432}

State PQC projects centered on maternal opioid use and Neonatal Abstinence Syndrome (NAS) have typically chosen as their initial focus increasing the rates of individuals screened with a validated Substance Use Disorder screening tool during pregnancy and establishing referral protocols for patients that screen positive on the maternal side of the dyad, and implementing the Eat Sleep Console care tool and non-pharmacologic interventions for the treatment of NAS, standardizing diagnosis of NAS, and helping to coordinate the implementation of Plans of Safe Care on the infant side of the dyad.\textsuperscript{433} By focusing on universal verbal screening rather than urine drug testing and by establishing systems of referrals to Medication for Opioid Use Disorder (MOUD) treatment centers, the initial scope of these PQCs reflects the focus on small improvements that can be made in a hospital setting that is characteristic of the PQC approach to earlier initiatives focus areas.
However, due to the stigma that accompanies pregnant individuals using substances (and individuals using substances in general) the focus on screening and creating referral pathways is, at best, incomplete.\textsuperscript{434} In the context of caring for an individual with a chronic health condition that carries stigma and shame attached to it, merely asking questions about an individual’s use of substances and then scheduling a follow-up appointment with a new provider is largely ineffective.\textsuperscript{435} Despite uniform recommendations that supportive, nonpunitive, integrated care for pregnant and parenting individuals using substances, obstetric provider discrimination against individuals who use substances, fear of Child and Family Services removing the child(ren) from the parent, and guilt over the substance use itself all present barriers to patients honestly answering the verbal SUD screening tool questions or receiving adequate, supportive follow-up care when they do.\textsuperscript{436} Moreover, when creating care pathways for pregnant and parenting individuals using opioids, most PQCs prioritize referrals to access MOUD specifically and not necessarily other behavioral health services such as therapy, despite the high correlation between substance use and past experiences of trauma, co-occurring mental health conditions such as anxiety and depression, and other social determinants that could benefit from therapeutic intervention such as intimate partner violence.\textsuperscript{437}

Without more robustly tying their efforts to a more holistic approach to caring for this patient population, PQCs may not be able to make the type of impact they would hope to make in reducing overdose deaths and improving health outcomes. An example of this is the Illinois Perinatal Quality Collaborative (ILPQC), which has, by all accounts, one of the most successful OUD initiatives of any PQC in the country—they have substantially improved each of the measures they are tracking around improvement opportunities, including verbal screening rates and referral to treatment.\textsuperscript{438} Despite their overall initiative success, rates of maternal death due to
opioid overdose have not lessened, and in fact, now rank (along with other mental health conditions) as the number one cause of maternal death in the state of Illinois. If PQCs can claim success for an initiative without a reduction of deaths caused by the condition they claim to have more adequately treated, we have to ask if the approach being taken is as effective as it could be.

b. Beyond Treatment: Examining the Potential Role of Perinatal Quality Collaboratives in a Recovery Model of Opioid Use Disorder

In recent decades, treatment of substance use disorders has shifted from an abstinence/treatment model to a recovery model of care. Substance Abuse and Mental Health Services Administration (SAMHSA) defines recovery as, “a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential.” As can be seen from this definition, recovery is a process that is unique to the individual and focuses on overall health, wellness, and the ability to live a meaningful life, as defined by the individual in recovery. Substance use is not explicitly mentioned in this definition—not only because the recovery model cuts across multiple behavioral health conditions—but because the goal of recovery is not the absence of substance use in a person’s life. The goal of recovery is to allow an individual to live a life that fulfils their individual potential: the reduction or elimination of substance use is merely a means through which to move towards this goal.

If PQCs want to prioritize substance use in pregnancy in any real, meaningful capacity, they need to do so within a recovery approach to substance use disorders. This entails prioritizing goals, interventions and measurable outcomes that are meaningful to pregnant and
parenting individuals with Substance Use Disorders. These goals can be linked to clinical outcomes such as entrance into MOUD treatment programs, but participation in an MOUD program alone should not be the goal. The centralized focus on MOUD in particular has already contributed to the “double bind” that pregnant patients with OUD experience in considering their medication choices: patients feel pressured into taking MOUD by their providers because of its efficacy in preventing overdose but adherence to their medication can result in short-term withdrawal symptoms in their newborn, which they are then often blamed and shamed for by their child’s care team.

While many PQCs have a stated goal to incorporate the voices of lived experience into their collaboratives, the design of initiatives reflect an emphasis on the inclusion of patient voice, but not necessarily the centering of this voice in the creation of the initiative itself. A notable and laudable exception to this is the Ohio Perinatal Quality Collaborative, which has taken steps such as convening focus groups, incorporating voices of lived experience as central members of their planning structure, and having patients work directly with hospitals teams. This ensures that the voices of lived experience are being brought to the table prior to the structure of the initiative being established, and that the initiative itself is not merely the adoption of an AIM patient safety bundle, without location-specific context about what patients in their state need in order to access care and feel supported in their care. As has already been discussed, and as will be discussed further in the following sections of this chapter, PQCs also need to include a more explicitly broadened approach to their consideration of how to improve care for this patient population. Unless if coordinated efforts work to improve the experiences of pregnant and postpartum individuals with OUD across the entirety of their pregnancy and postpartum period are undergone, we will continue to fail this patient population and their families.
III. Examining the Role of Expanded Collaborative Relationships in Promoting Substance Use Disorder Recovery

In order to understand how we have arrived at our current understanding of OUD, and why the laser focus on OUD specifically rather than on Substance Use Disorders (SUD) as a whole is inequitable and short-sighted, we have to first understand the history of SUD treatment in the United States and how it has shaped our current state.

a. The History of Substance Use Disorder Treatment in the United States

The history of how Substance Use Disorder (SUD) is understood and how SUD is treated in this country has always been heavily impacted by racial and gender power dynamics. While psychoactive substances have been a part of many cultures and cultural practices, the use of substances as a potential harm and therefore efforts to treat or abate use in the US began with efforts in the 1750s by indigenous peoples to help lessen the use of alcohol. The identification of alcohol as an addictive substance for which one might need treatment was echoed by Benjamin Rush, whose writings were used as a foundation for the beginning of the temperance movement. Alcoholism was seen as a significant public health crisis at this time, as it led to men being unable to work, domestic violence, and a slew of additional health conditions. From this time period up until the early 1900s, the majority of treatment efforts centered around treating alcoholism. During this time period, various other substances were introduced as treatment for alcohol overconsumption, including cocaine, opioids, barbiturates, and amphetamines. Treatment options for patients with alcohol use disorder and morphine use disorder were rife with exploitation and human rights violations, including the use of experimental and dysregulated drugs at “narcotics farms,” the indefinite placement of individuals
with alcohol use disorder in asylums, and the passing of legislation in several states that allowed for the sterilization of individuals with alcohol or other use disorders in order to improve their “moral condition.”

While treatment options and overall understanding of SUDs was always marred by stigma and misunderstanding, the “crack epidemic” of the 1980s and the subsequent “War on Drugs” that resulted, marked a time of pivoting societally from viewing SUDs as a public health crisis (albeit a public health crisis that was thought to be caused by the moral failure of the individual) to a criminal act that necessitated incarceration and punishment. As will be explored in Chapter Five of this dissertation, the use of crack cocaine in low-income Black and Brown communities was viewed as criminal activity that required incarceration, and the use of crack cocaine was said to be the cause of many adverse health effects in children, none of which were grounded in scientific evidence and all of which have since been disproven. The criminalization of drug use fueled the burgeoning prison industrial complex in the United States, with drug offenses being the number one cause of incarceration in this country, even currently in 2022, with 45.2% of individuals currently incarcerated due to drug offenses. During this period of time, White individuals were shown to be using cocaine at the same rates as Black individuals, but were routinely sent to drug rehabilitation facilities or not reported to the police by healthcare professionals when they were identified as someone using a substance at the rates at which their Black counterparts were. This resulted in a context in which substance use was criminalized for some but not for all, and the criminalization of substance use in pregnancy and postpartum period for Black families in particular has led to devastating effects on families and communities alike.
This context of criminalization is important in understanding the shift that the opioid epidemic has brought in recent years in how substance use is conceptualized and treated. The Center for Disease Control have identified three waves of the opioid epidemic: the first wave beginning in the 1990s with an increase of prescribing of opioids and an increase in overdose deaths linked to prescription opioids beginning in 1999, a second wave starting in 2010 with an increase in deaths that involved heroin, and a third wave beginning in 2013 with an increase in use and overdose deaths involving synthetic opioids—most notably, fentanyl. The number of overdose deaths in recent years have continued to climb, with 68,630 individuals dying from an overdose in 2020. With this increase, there has also been a stark increase in the racial disparities in overdose death, with an increase of 38% in the rate of opioid overdose deaths from 2018 to 2019 in Non-Hispanic Black individuals despite the rates for other race and ethnicity groups remaining the same or decreasing. While there are many factors that might contribute to this disparity, the continued criminalization of substance use in Black individuals in particular and the double bias of healthcare providers have been posited as key factors in why Black communities are seeing an increase in overdose deaths.

When it comes to Opioid Use Disorder in particular, there have been efforts in recent years to improve and coordinate care for this patient population, including the creation of centers to administer Medication for Opioid Use Disorder (MOUD), the creation of additional residential and inpatient treatment programs, extensive education for providers about prescribing opioids, and promotion of the prescribing of Naloxone, which is proven to reduce overdose deaths when administered. Despite this, many barriers to providing this patient population with the care they need exist, including fragmented care, difficulty accessing care, and continued bias, stigma, and misinformation on the part of healthcare providers when it comes to substance use disorders,
which compounded by other factors such as systemic racism. While progress has been made in attempting to re-shift the understanding of SUDs from criminal acts that need to be punished to health conditions that should be treated appropriately, there is still significant work that needs to be done.

**b. The Need for Expanded Collaborative Relationships in the Promotion of Substance Use Disorder Recovery**

Substance Use Disorders are chronic, longterm illnesses that can occur at any point in an individual’s life and that significantly impact the entirety of an individual’s daily experience and relationships. Given this, support in recovering from an SUD is needed across every aspect of an individual’s life: from community-based and outpatient resources, from family and social supports, from peers with shared lived experience, and from healthcare providers. In order to fully support pregnant and postpartum individuals with SUDs, there must be a balance between resources and treatment that is tailored specifically towards the unique needs that an individual experiencing a pregnancy might have and the continued, persistent needs that an individual with an SUD would need, regardless of pregnancy status. This requires an increase in resources such as inpatient and residential treatment centers that allow pregnant individuals (as many of these existing programs have pregnancy as an exclusion criteria) and an increase of inpatient and residential treatment programs that allow babies and children to stay with their parent as they receive treatment.

In addition to the increase in more specialized treatment options, we need to develop systems where continuity and coordination of care for individuals with SUD is supported and encouraged, while still protecting the privacy and autonomy of individuals seeking treatment.
One of the biggest current barriers to coordination of care currently is the lack of communication between different providers in this patient population. However, this lack of communication on the part of healthcare professionals who provide SUD treatment is well-justified, particularly in the context of pregnant and postpartum individuals, as healthcare professionals in other specialties have still been shown to provide biased, unsupportive care to individuals with SUDs and in some cases involve the criminal justice system even when that is not a legal requirement, leaving patients unwilling to consent to the sharing of their relevant health information between providers. Catered solutions such as a healthcare record platform in which patients can select which information from their individual EHR record are shared amongst providers, or other patient-driven information-sharing strategies might be one way in which to promote coordination without compromising the autonomy of the individual patient.

IV. Towards a Critique of Perinatal Quality Collaboratives

While there are benefits to the PQC model, there are also several limitations to this framework, which will be discussed in this section.

a. Limitations of the Perinatal Quality Collaborative Model

Continuing to use Opioid Use Disorder Initiatives as an example, we can see that the traditional PQC framework has many limitations, particularly when PQCs attempt to address health inequities or care for patients who face discrimination and stigma due to their health conditions, socio-economic status, or race. Given this, and given the persistence of health inequities and injustices rooted in racism in particular, there are been questions in recent years about the success or appropriateness of the PQC model in addressing health inequities and
system racism—most notably, from leading perinatal substance use disorder expert, Mishka Terplan.469

Terplan has noted that Ford and Airhihenbuwa’s Critical Race Theoretical framework maps well onto the quality improvement approach that PQCs adopt, and in particular, the use of driver diagrams in structuring initiatives.470 By conducting quality improvement projects that center on improvements made at the hospital level, with metrics and goals selected largely by clinicians and quality improvement advisors, PQCs have only been able to make strides on specific elements of caring for individuals with Opioid Use Disorder in the pregnant and postpartum period, most notably, increasing the number of patients screened with a validated Substance Use Disorder screening tool during the course of their pregnancy.471 However, these efforts have largely not yielded decreases in negative health outcomes associated with maternal opioid use, a decrease in overdose deaths during the perinatal period, or a reduction in associated disparities in care and health for women of color who use opioids during their pregnancy or in the postpartum period, even in states whose PQCs have seen success in other initiatives.472

To be successful in making improvements to eliminate health inequities, PQCs must reconsider their efforts and restructure their approach to center those who are most impacted. In the words of Terplan: “to capture structural and intersectional domains, data collection must be oriented to social theory—something that can only be accomplished by centering the PQC on the most marginal rather than the mainstream.”473 To more fully understand what this approach might entail and its theoretical foundations, we should consider the Critical Race Theoretical framework in a public health context, as proposed by Chandra Ford and Collins Airhihenbuwa. Ford and Airhihenbuwa argue that Critical Race Theory (CRT) is needed in public health to understand the root causes of health disparities because it, “encourages the development of
solutions that bridge gaps in health, housing, employment, and other factors that condition living.” Critical Race Theory is able to draw across these different arenas because it, “integrates transdisciplinary methodologies that draw on theory, experiential knowledge, and critical consciousness to illuminate and combat root causes of structural racism.” Because the methodology itself is both explicitly centered around considerations of equity and requires the involvement of experiential knowledge, this approach is inherently multidisciplinary and collaborative in nature. CRT also requires an approach that “centers the margins” i.e. that takes as its starting point the lived experience of those most impacted by the inequities that exist and which one is trying to understand.

The iterative, multi-disciplinary CRT approach does, indeed map on well to a quality improvement (QI) approach because QI is also inherently iterative and requires the development and continued work of a multidisciplinary team. But the ways in which PQCs currently structure, design, and perform their initiatives—and in particular, their hospital-centric approach that does little to challenge the inherent hierarchies that exist in healthcare currently—do not center the margins in a manner that would allow for meaningful overturning of the structures that create and inform health inequities. Chapter Five of this dissertation will explore this dynamic more in depth and offer potential considerations for how PQCs might move forward, but for the purposes of this chapter, it is enough to note that this failure to challenge the current status quo entails a major limitation of the current PQC model.
b. For What Are We Responsible? Considering the Efficacy of Hospital-Led Quality Improvement Efforts

An enormous amount of time, funding, and resources have been poured into the formation and continuation of quality improvement (QI) efforts at the hospital level within the perinatal space. While hospitals already have QI departments and resources devoted to improving quality overall, the urgency of the maternal mortality crisis, as well as concerning infant health outcomes has led to additional resources being devoted to QI for these specific patient populations through the creation of PQC, the National Network of PQC, and AIM. The initial success of PQC and AIM projects in improving response to postpartum hemorrhage, the identification and timely treatment of severe hypertension for patients on Labor & Delivery, and the reduction of primary cesarean section rates were used to bolster the claims that PQC and hospital-led efforts to reduce maternal mortality were an effective strategy, and one which should be adopted by every state in the effort to reduce maternal mortality rates. And indeed, without a doubt, hospital-based efforts to improve quality of care are still needed, given the number of preventable maternal deaths and severe maternal morbidities that occur at the inpatient level due to error or negligence on the part of medical staff. The substandard care that patients receive in hospitals has an impact on the health of the dyad and hospitals have a responsibility to do everything they can to improve the quality of care patients receive at their institutions.

However, when we consider both the time periods and the causes of maternal mortality, the vast majority of deaths occur outside of the inpatient stay. With over 65% of death occurring either in pregnancy or in the postpartum period, it is clear that there are significant efforts that need to be made to better support individuals in these time periods. Moreover, when we consider the causes of death, many of these have scope and impact far beyond what can be
identified and addressed within an inpatient hospital stay. Rising causes of maternal death include: overdose as a result of Substance Use Disorders, domestic violence, and mental health conditions that influence other causes of death or result in suicide. While there is a small role that inpatient teams can play in improving care for these patients, including verbal screenings to help identify if a patient might be experiencing any of these situations and linkage to outpatient resources, this role is not a primary role, or the most impactful role in adequately caring for them. Despite this, PQCs and at times, participating hospitals, continue to receive significant amounts of funding and resources to perform initiatives related to these patient populations on the federal and state level. As we have already discussed in this chapter, however, even successful PQC initiatives in these spaces have not resulted in the reduction of maternal mortality rates for the patient populations that are targeted.

This is because the emphasis and the material support for hospital-led QI efforts when it comes to these patient populations is misplaced. While hospital teams can exacerbate and worsen the health of individuals through their treatment of them, for the most part, factors such as SUD, mental health conditions, and domestic violence have the greatest impact on an individual’s life outside of the inpatient setting, and the efforts to improve care for these patients—as well as the funding and allocation of resources for these efforts—should be given to the individuals and organizations that are providing care for them while they are in their communities. An example of what this type of resource allocation might look like is Merck for Moms “Safer Childbirth Cities” Initiative. Safer Childbirth Cities launched in 2018 and provided $500 million in funding to cities with high rates of maternal mortality rates (and high rates of racial inequities in maternal health outcomes). Notably, Merck for Moms allotted this funding to community-based organizations with partnerships and ties to other community-based resources within their city,
with the goal of strengthening collaborative community efforts to improve health outcomes and reduce disparities, and in order to help community-based organizations build an infrastructure to improve their ability to serve their own communities.

Community-based organizations have the potential to impact the health of families both before and after birth in a way that hospital teams do not, and the efforts of community-based organizations have been vastly underfunded, especially when compared to the resources allotted to hospitals within this space. In order to effectively improve maternal health outcomes, we need more efforts in the vein of Safer Childbirth Cities that pour funding, access to resources and support, and collaborative problem solving into organizations that serve highly-impacted communities on a daily basis. Everyone has a role to play in improving the health outcomes of new families, but for far too long the emphasis and allocation of material resources has been unbalanced in a manner that favors hospitals and hospital-based improvement efforts. Hospitals need to continue to work to improve the care that they provide, but they must no longer be the primary focus of our efforts.

V. A Reproductive Justice Approach to the Perinatal Quality Collaborative Model

Balancing the scales and widening the network of who should be involved in our robust efforts to improve maternal and infant health outcomes is required if we are to make a substantial improvement in the movement for overall improved outcomes and health equity in this space. Reproductive Justice entails the freedom to live and raise one’s children in safe environments, which will necessitate stronger, more collaborative relationships across the continuum of care that support more just communities.
a. What We Mean When We Talk About Collaboration: The Role of Relationships in the Movement Towards Transformational Change

When discussing the vital need to speak about both the oppression she faced and the liberatory future she sought to create, Audre Lorde invoked the principle of Ujima: “collective work and responsibility—the decision to build and maintain ourselves and our communities together and to recognize and solve our problems together.” The need to create language to speak about and in service of justice was important to Lorde, not only because she was a writer, but because she recognized that human beings are inherently relational in a manner that necessitates a collective and community-centered approach to liberation due to our interdependent nature. Both widescale and individual change requires transformational relationships, because our lives and communities happen in and through relationship.

In thinking about the role that relationship plays in liberatory efforts, it is significant to note that the word relationship finds its origins in the fourth principle part of the Latin verb “ferre”—to bear, carry, suffer, or endure—and the prefix “re”—a prefix which indicates both repetition and a return to an origin; a beginning that is also inherently tied to its source. Relationship requires us to endure and carry ourselves through the present moment into the future, beginning in the present moment while, in a sense, returning to our original state of interdependence. This carrying together requires not only that we work together, but that we love one another, in the sense articulated by bell hooks in the penultimate chapter of all about love. According to hooks, who draws from her interpretation of Biblical texts, love requires compassion for one another but also forgiveness, the release of shame, the dispelling of fear, and an ongoing commitment to hope. Love also requires that we, “surrender the will to power… [and] our attachment to power.”
In considering many of the current structures that we have discussed thus far in this dissertation, it is clear that these structures not only do not promote relationship, but actively hinder it. Within a healthcare environment that prioritizes reducing threat of legal liability, healthcare providers feel that they cannot communicate honestly about the role they have played in harming patients and the opportunity for forgiveness is denied. Within a conceptual framework of safety that prioritizes merely the absence of physical pain and the reduction of errors, healthcare organizations and individual healthcare providers act from a position of fear: at times, fear of their own capacity to fail, but also out of fear of their patients they deem to be “at-risk” or “problematic.” Health systems and community-based organizations cannot form meaningful relationships in our current structures of healthcare reimbursement because hospitals are encouraged to cling to their power and the access to resources that it provides them.

Maternal and infant health outcomes are significant not only because each individual’s life is sacred, but also because the health of new families is indicative of the health of the future of communities. Therefore when we consider how we might create a future in which pregnancy and childbirth is not something to be feared in this country, this requires not only efforts to improve a series of services provided by healthcare teams, but a new conception of what communities would need to look like if they are to be the environments that will support and nurture new families. This imagining of community is inherently relationship-focused because in order for a community to serve all of its members, those members need to be involved in imagining what community would best support them and their needs. We all exist in community, and the future of our communities depends on our collective ability to imagine better communities and support their birth and continued existence. James Baldwin best articulated this sentiment when he wrote, “nothing is fixed, forever and forever and forever, it is
not fixed; the earth is always shifting, the light is always changing, the sea does not cease to grind down rock. Generations do not cease to be born, and we are responsible to them because we are the only witnesses they have. The sea rises, the light fails, lovers cling to each other, and children cling to us. The moment we cease to hold each other, the moment we break faith with one another, the sea engulfs us and the light goes out.”491

b. Decolonizing Our Networks of Care: A Reproductive Justice Approach to the Perinatal Quality Collaborative Model

“Where does our power lie and how do we school ourselves to use it in the service of what we believe?”492 This question, asked by Audre Lorde, is the central question that must be asked of each and every individual in relation to the maternal health crisis in the United States. If we truly believe, as society, that we have a responsibility to support the health and wellbeing of pregnant and postpartum individuals, the questions that guide our work should not be: “what do hospitals need to stop contributing to the preventable deaths of their patients?” but rather: “what do pregnant and postpartum individuals need, and how can we give those things to them?” By re-centering our efforts around the needs of the individuals impacted by the system’s current failings and explicitly tying those efforts to the individual relationship an individual, organization, or system has to the current failings of the system, we de-center the role of hospitals as the locus of power and of improvement efforts while reinstating individuals and communities as the central visionaries of the future communities that will support their well-being and flourishing.

In considering Nussbaum’s capabilities approach, Ada María Isasi-Díaz embraces the importance of interpersonal, reciprocal flourishing found in Nussbaum’s explication of
capabilities, but argues that the question of justice must always start first with those whom justice has failed. Isasi-Díaz argues that the poor and oppressed have historically been left out of conversations about decision making in society, which has resulted in further oppression of these groups and a double injustice or having not been considered an active participant in one’s reality. While the question of how to build just communities and a just world often hold those in oppressed situations as a topic of discussion, their voices have often not been taken into consideration or even brought to the table where discussion is taking place until very recently. The poor and disenfranchised have to be considered as moral agents, and justice should be conceived of as a “reconciliatory praxis of care and tenderness” if it is to truly be justice for all.

Isasi-Díaz argues that historically, colonialism and contemporary neoliberal political frameworks have destroyed the potential for justice by focusing on the individual. This individualistic mindset has ruptured relationships and led to the disenfranchisement of communities and individuals who need the most support of society. To move towards justice, society must learn to restore the familial and cultural bonds that were broken by colonialism and extreme individualism. It is in this sense that the praxis she envisions can be called reconciliatory: individuals must reconcile to heal communities torn apart. In this reconciliatory praxis, individuals come together to form a community in dialogue, whose aim is the creation of a shared future in which everyone, in Nussbaum’s terms, is given the nurturance to achieve what they are capable of. Isasi-Díaz’s conception of justice as a reconciliatory praxis of care and tenderness aligns with a Reproductive Justice approach because it both explicitly states that the fight for justice should begin with and center the voices of those who have been treated unjustly,
and because it links the justice of the individual to community justice, recognizing that justice must inherently occur through relationship and co-creation.

When considering the Perinatal Quality Collaborative Model, we can see that this model is, in a sense, unbalanced. By placing an overemphasis on the importance of hospitals and their needs and by de-emphasizing the role of community-based organizations and of patients and families, this model fails to live up to its full potential, even when patient voice is involved. While Chapters Five and Six of this dissertation will explore more nuances of how PQCs might shift and re-prioritize the ways in which their work is centered and the scope of what they might do, for the purposes of this chapter, it is enough to note that at minimum, PQCs need to expand their capacity to collaborate outside of their hospital-centric design so that their work can be driven by the individuals and communities they aim to serve, and so that they can fully live up to their role as a part of a community. In doing so, PQCs and hospitals can engage in a form of Isasi-Díaz’s reconciliatory praxis of care and tenderness by repairing their relationships to the rest of their community and allowing other voices to help shape what their role within community might look like moving forward.

Conclusion

Maternal health systems of care in the United States are broken. In order to improve the care that mothers and babies receive, it is not enough to focus on improvements that can be made in the hospital setting. Significantly improving health outcomes for mothers and babies requires conceptualizing, co-creating, and implementing new, coordinated systems of care that support and tend to the wellbeing of the mother-baby dyad in all of their dimensions. We must work together to create systems that allow families and communities to thrive and enact the inherent
potential that exists in the creation of new life. These systems must be inclusive, intentional, and
explicitly equitable in their conception and execution in order to address the inequities and
injustices that exist within our current, broken systems. To borrow a metaphor from Daniel
Dawes, if our communities are orchards, we must build systems that allow each tree to grow to
its optimal level of health.\textsuperscript{498} This cannot be accomplished without true partnership and
collaboration across all levels of care.
Chapter 5: Safety and Quality

Most of us are about as eager to be changed as we were to be born, and go through our changes in a similar state of shock

- James Baldwin

5a. An Ethical Argument for the Adoption of Value-Based Bundled Payment Models in Maternal Health

Introduction

Building systems of care that support the health, wellbeing, and flourishing of individuals, families and communities not only requires that individual caring relationships and healthcare organizational policies reflect a dignity-enhancing approach—it also requires the ability to pay for needed care. The following sections will address the need for insurance reimbursement models that reflect a patient-centered approach to care, as well as the need to measure quality of care in a way that reflects what matters most to patients.

I. The Role of Healthcare Payment Models in Supporting Competence

While healthcare payment models may not at first glance seem substantively linked to competent healthcare, the way in which healthcare workers are reimbursed for their caring services has a large role to play in either supporting or inhibiting competent care.
a. The Role of Competence in an Ethics of Care

Tronto associates competence with the third phase of caring: care-giving.499 Care-giving, as one would anticipate, entails, “the direct meeting of needs of care.”500 However, Tronto specifies that care-giving in this context refers specifically to meeting the needs of care in a direct, substantial way—usually through labor that directly involves the person(s) for whom you are caring. This means that direct caring work such as a nurse administering medication to a patient falls under the umbrella of care-giving, but more indirect actions that require additional work to address caring needs, such as donating money to a charity, would not.501 This distinction is important to note in the context of our subsequent discussion of healthcare payment models because “money does not solve human needs, though it provides the resources by which human needs can be satisfied.”502

When Tronto writes of competence in care-giving as a moral necessity as well as a moral quality of care, she does so to ensure that competence, or successfully following through on caring attempts, is an integral part of the caring process and is seen as having a moral dimension.503 To illustrate this distinction, Tronto uses the example of a teacher at a low-resourced school who is forced to teach a subject with which he has no familiarity who ultimately does not succeed in teaching his students due to his own incompetence when it comes to the subject matter. Competence is such a vital component of the caring process within this example because if this situation was considered from the perspective of the larger school administration, they would argue that they had taken care of the needs of their students by assigning them a teacher and therefore enabling a class to take place. However, just because a class took place it did not mean that the students were actually educated. The incompetence of the teacher led to a failure of care for his students and he should take responsibility for the part
he played in this failure by agreeing to teach a course he knew he could not teach, but the failure of this care does not rest of the shoulders of the teacher alone. The school administration, in insisting that a teacher without the necessity education to provide adequate instruction to his students teach a class anyway, also directly contributed to the failure of care.

In this way, competence as a moral quality of care is something for which multiple entities hold responsibility in most contexts. In a healthcare setting, individual healthcare workers are responsible for ensuring that they have the necessary education and skills to successfully perform the tasks that they have been asked to perform on behalf of their patients. The organization that employs them also has a responsibility to ensure that they are not asking or coercing their employees into taking on responsibilities that fall outside of their abilities. These two elements of competence and its relationship to competence are the most robustly explored by Tronto, but there is a crucial additional element to consider when thinking about the shared responsibility for competence, particularly in a healthcare setting: the way in which healthcare organizations and healthcare providers are being paid and how the structure of reimbursement contributes to or actively inhibits the competence of individual providers, individual organizations, and even systems of care.

b. The Role of Healthcare Payment Models in Supporting Competence in Healthcare

As Porter and Lee explain, the way in which health care services are reimbursed both directly depends upon how medicine is being practiced while also greatly influencing the ways in which the practice of medicine is able to continue and change over time. While this claim may seem accurate in a rather self-evident way, it is easy to underestimate the impact that reimbursement models can have on the daily practice of medicine and the design of systems of
care themselves, particularly in a societal context in which hospitals and other healthcare organizations function primarily as businesses and places of healing as a secondary function.\textsuperscript{505} For decades in the United States, the primary model of healthcare reimbursement was a fee-for-service model in which providers are reimbursed for providing specific services to patients. Within this model, the amount of money any provider receives is determined by the number of services she performs and is for the most part (and within reason) not linked to or influenced by other relevant contextual factors such as health outcomes, patient satisfaction, etc.\textsuperscript{506} As many scholars have argued in recent years, this model is detrimental for a myriad of reasons, including economic.\textsuperscript{507} However, for the purposes of this chapter, we will focus primarily on the impact that a fee-for-service model has on the quality care and the manner in which care is conceptualized and enacted when conceived within a fee-for-service model of reimbursement.

Within a fee-for-service model of reimbursement, providers and healthcare systems are reimbursed for performing specific procedures or services at rates that are determined by factors such as the credentials of the person providing the service, the level of difficulty of the service, and the amount of time it takes to perform the service.\textsuperscript{508} At first glance, this might not appear to be a problem, and might, in fact, seem to make sense intuitively: there are many jobs in which this type of payment model is also used, such as plumbing, contractors, etc. However, when we consider the nature of medicine and the context in which these services are being conducted, there are issues that arise. The purpose of health care is to help support and improve the health of those seeking care, which might require different number of treatments, different amounts of time spent to adequately accomplish a proposed treatment, and varying degrees of follow-up depending on the individual and their particular health status and individual context. When we reimburse “for procedures performed rather than outcomes achieved” there is no financial
incentive for providers or health systems to provide good care. Instead, the financial incentive lies in providing more procedures.\textsuperscript{509} Within a social and economic context in which hospitals are required to be successful businesses in order to survive, and in an increasingly competitive financial landscape, health care systems not only do not have an incentive to provide good care, but in fact have an incentive to build their entire infrastructure around optimizing the amount of services they can perform and bill for in order to stay open.\textsuperscript{510} This has resulted in healthcare systems that prioritize the quantity of services provided over the health of their patients and the wellbeing of their staff.

II. Value-Based Bundled Payment Models: A Response to Patient and Provider Needs

If fee-for-service reimbursement models contribute to the establishment and maintenance of unhealthy systems of care, the question then arises: what type of payment model might support the creation and sustainment of more caring systems?

a. Value-Based Bundled Payment Models: An Introduction

One promising reimbursement model that has gained traction in recent years is the value-based bundled payment model. While there are different iterations and conceptions of what a value-based bundled payment model might entail, for the purposes of this chapter we will focus on the value-based bundle payment model as originally proposed by Michael E. Porter and Elizabeth O. Teisberg given its focus on value as defined as what is meaningful and significant to the patient in particular.\textsuperscript{511} Within this model of reimbursement, the goal of the reimbursement systems itself is to “improve the value delivered to patients” where value is defined as a measurement determined by “the patient outcomes achieved per dollar expended.”\textsuperscript{512} Simply
put, a value-based bundled payment model entails a shift “from a supply-driven health care
system organized around what physicians do and toward a patient-centered system organized
around what patients need.” This shift requires a reorientation of health care systems
themselves from a series of service provided to a coordinated, continuous process of services that
provide different types of needed care towards a unified goal of better health for the patient.

The reimbursement structure of value-based bundled payment models entail payments
that cover care “cycles” that range from the entire cycle of acute medical conditions, primary
care for specific patient populations, and care for chronic conditions over a defined period of
time. These models also adjust for nuanced situations such as providers who take on “high-
risk” patient populations and penalties for providers whose patients experience preventable
complications as a result of failed care. In recent years, value-based bundled payment models
have been gaining popularity in both the United States and other countries, with value-based
bundled payments now the established norm for organ transplants in the US.

When combined with mandatory reporting of patient outcomes and an emphasis on a
multi-disciplinary team-based approach, the adoption of value-based bundled payment models
have shown to spark innovation in care mechanisms while also proving to be cost-effective.
By adopting an approach that is also oriented around care cycles that have a distinct scope and
delineated period of duration, value-based bundled payment models are also exceptionally well-
suited to provide structure and monetary support for caring processes that entail an acute care
episode. As we shall see in the next section, pregnancy is one such example of a care cycle that
can benefit from the structured, team-based approach a value-based bundled payment model
promotes through its reimbursement strategies.
b. The Impact of Implementing Value-Based Bundled Payment Models for Pregnancy Episodes

Under traditional fee-for-service models of care, caring for the whole individual during a pregnancy can be a fragmented, disjointed process that is exceedingly expensive for the individual while also leading to many missed or failed opportunities to access needed care. Over the course of a pregnancy, an individual may need prenatal OB-GYN appointments, an inpatient stay in Labor & Delivery, and postpartum OB-GYN appointments, but these appointments are only the bare minimum of care recommended to patients, with many individuals requiring additional care within their pregnancy. Conditions such as perinatal mood disorders, severe hypertension and preeclampsia, and substance use disorders are often identified during pregnancies and require immediate, substantial response in order to support a healthy pregnancy and healthy family.

Pregnancies do not happen in a vacuum: individuals who become pregnant enter their pregnancy with past health conditions and often develop additional health conditions throughout the course of their pregnancy. These conditions may not be caused by the pregnancy itself, but they can determine the health outcomes of both the pregnant individual and their child. In order to optimally care for the dyad during pregnancy and beyond, the systems of care that patients navigate should be as streamlined and coordinated as possible and must center the health and wellbeing of the dyad as the ultimate goal of care. By implementing a bundled payment model for an episode of pregnancy, we can streamline coordination of care, ensure that mothers do not lose healthcare coverage in the postpartum period, and provide coverage for conditions that occur during a pregnancy episode but are not caused by the pregnancy itself.
One example of the way in which a value-based bundled payment model has been developed and implemented around pregnancy in a manner that promotes positive systemic changes to the way in which individuals receive care is the 2019-2020 work of the Pennsylvania Perinatal Quality Collaborative (PA PQC) Policy Group. In the latter half of 2019, the PA PQC convened a group of diverse stakeholders including providers, health plans, and community-based organizations to determine priorities and recommendations for a value-based bundle payment structure for the state of Pennsylvania. The group’s recommendations were informed by relevant statewide data around causes of maternal mortality and severe maternal morbidity, as well as the overall greatest opportunities for improvement in health outcomes for pregnant and postpartum individuals. Specific categories for improvement that were grounded in best practices/standards of care set by professional organizations such as ACOG were selected by the group and mandatory quality measures to inform improvement efforts were then agreed upon by consensus.521

The Policy Group decided the following improvement categories should be the backbone of the model: Health Equity and Social Determinants of Health, Substance Use Disorders, Cardiovascular Conditions, Expanded Postpartum Care, Perinatal Mental Health, Pre-term birth policies, Prenatal Care, Newborn standards of Care, C-Section, Vaginal Birth After Cesarean (VBAC), and Elective Delivery.522 By selecting these categories, the recommendations of the group respond to the identified needs of the state’s population by centering the mechanism of reimbursement around responsiveness to the overall health of the dyad. Within the recommendations of this model, providers and health systems are rewarded for healthy moms and babies, not how many individual services they are able to provide. By determining statewide recommendations, adopting the model not only supports the health and well-being of individual
patients, but also directly supports the health and wellbeing of communities across the state. The recommendations of the group will also be revisited periodically so that additional needs can be evaluated and incorporated as they arise and the condition of communities change over time.

While the adoption of the PA PQC Recommended Standards of Care and Quality Measures for Perinatal Value-Based Payment Models is voluntary, many of the major health plans across the state have already adopted this model due to their participation in the Perinatal Quality Collaborative. Through its adoption, Pennsylvania has the potential to set the benchmark for how reshaping the way in which care is paid for can influence the way in which care is delivered. By viewing pregnancy as a complete episode as opposed to its composite parts, as is typically the case in traditional reimbursement models, states can improve coordination of care, provide coverage for types of services that are not typically covered as a pregnancy-associated condition, and make coordinated efforts towards improving health outcomes for patient populations statewide.

III. Expanding Pregnancy Episodes: Promoting Competency in the Postpartum Period

Recent efforts to support improvement in maternal health outcomes on the federal level have centered around the importance of improving postpartum care, including expanding Medicaid coverage for one year postpartum. In order to understand the emphasis on extended coverage and the role it might play in improving health outcomes, we must first understand the extent to which patients are currently often not receiving the care they need after giving birth.
a. An Examination of the Failure of Health Systems to Care for Postpartum Patients

As has already been explored in previous chapters of this dissertation, the greatest number of pregnancy-associated deaths in the United States occur within one year after delivery. While there are many factors that contribute to this statistic, an overarching theme that cuts across many of the leading causes of death in the postpartum period is that patients do not receive adequate support (via visits, patient education, follow-up, etc.).

In their Committee Opinion “Optimizing Postpartum Care,” ACOG states that “postpartum care should become an ongoing process, rather than a single encounter, with services and support tailored to each woman’s individual needs.” Despite this recommendation, and despite the fact that care for infants begins immediately after birth and unfolds in continued intervals within the first year of the baby’s life, postpartum individuals often only receive one postpartum appointment, which often does not occur until four to six weeks after birth.

In an attempt to better understand both what patients’ experiences of the postpartum period currently entail and how they might be improved, a research team in Chicago conducted a qualitative study in which new mothers were asked about their experiences during their child’s well-baby visit. Over the course of this study, the following themes arose: women felt that having postpartum care was important; they wanted continuity of care prenatally and postpartum by having more contact postpartum with their prenatal practitioner; the current multiple barriers to care made it difficult for patients to put into words what their “ideal” care would look like in the postpartum period; improving the content of what was involved in the postpartum visit would increase attendance; convenience of postpartum care for women is key; and postpartum care should also be included as a part of their child’s well-baby visit, including depression screening and contraceptive counseling. This study also indicated that even when options for postpartum
care were offered to patients, they were often unable to attend their appointments due to issues such as lack of transportation, lack of child-care and/or child-friendly spaces for their children to go during their appointments, and the inability to take off work for both their child’s appointments and their own.

The most significant changes that need to occur in the context of postpartum care in the United States can be easily summarized: “convenience and continuity of care.”

Postpartum individuals are navigating a complex healthcare system with a myriad of additional new stressors and the responsibility to care for a new life and their own healing body. The current system of caring for postpartum individuals does not adequately address the needs of many new families because it is non-relational, does not accommodate social and economic contexts that effect the individual’s ability to attend appointments, and does not function in a way that is convenient for patients.

b. An Ethical Argument for Expanding the Pregnancy Episode

The current definition of a pregnancy episode- in both reimbursement and in how our system of care is structured- fails to support postpartum women because it is structured to prioritize only the successful delivery of a child without fully considering the enormous impact that bringing a new life into the world entails. When considering the balance of care and consideration that both sides of the dyad receive, we can see that our systems of care are weighted to more fully consider and support the health of the baby, and fail to support the health and wellbeing of mothers after they have successfully given birth. This creates difficulties across the board because even if one is trying to prioritize the health of the baby, it is difficult to do so if the baby’s parent is unwell. Moreover, the perception of which mothers “deserve” empathy and
compassion when they are unwell and which mothers are blamed or shamed for their illness is hugely impacted by stigma, bias, and cultural conceptions. Black mothers, low income mothers, and mothers with stigmatized illnesses such as Substance Use Disorders have all been found to receive lower quality of care than White mothers from higher socio-economic statuses due to factors such as implicit bias of healthcare providers and provider misinformation about the nature of substance use disorders. In the case of “mother blame” narratives that target Black mothers in particular, mothers are attributed disproportionate blame for the health outcomes of their children, even in cases where adverse health outcomes are not linked to the mother’s behavior. When it comes to mothers with health conditions such as Substance Use Disorders, many providers and nurses still believe that these disorders are the result of moral failings and are volitional, rather than chronic illnesses that need to be treated as such. Chapter Six of this dissertation will explore the ways in which patient (mis)treatment and provider empathy is shaped by factors such as race, socioeconomic status, and stigmatized health conditions in more depth, for the purposes of this section, it is enough to note that bias in care based on perceived fault for the patient’s own and their baby’s health exists and that perinatal period is, in words of maternal substance use disorder researchers, “a timeframe particularly subject to bias.”

A more balanced approach to caring for the dyad necessitates an expansion of the pregnancy episode to include more robust care longer into the postpartum period because even though the baby has already been born during this period of time, there are significant physiological and environmental changes that occur during the postpartum period that impact the health of new and expanding families and that are a direct result of pregnancy. ACOG has recommended that the following components should all be considered key elements of
postpartum care: “mood and emotional well-being, infant care and feeding, sexuality, contraception, and birth spacing, sleep and fatigue, physical recovery from birth, chronic disease management, and health maintenance.” Caring for all of these components inherently cannot occur in the context of one postpartum follow-up visit, but instead requires an ongoing process in which patients receive ongoing support and tend to any physical, emotional, and psychological needs they, their child, or their family may have. If the overarching goal of maternal care is to ensure the health and wellbeing of both babies and mothers, the pregnancy episode must include support and care needed to ensure that mothers are able to recover from the birthing process and tend to their needs as they nurture new life.

IV. Who Gets to Care? Expanding Coverage in the Peripartum Period

While community-based organizations have provided vital care to support the health of postpartum families, they have largely not been compensated for their services in a manner that recognizes their services as vital health care.

a. The Role of Community-Based Organizations in Providing Essential, Competent Care in the Peripartum Period

While the formal health systems have often failed to provide the care that new families need, community-based organizations and resources have tried to fill in the gaps of care for these families by providing support, access to needed material goods and transportation, and education. Despite lack of access to resources and necessary funding, community-based organizations have provided vital health care to their communities and they deserve to be compensated fairly for that care by health insurers.
In 2018, the Alliance for Strong Families and Communities and the American Public Human Services Association (APHSA) commissioned a report titled, *A National Imperative: Joining Forces to Strengthen Human Services in America.* This report details, “the economic and social impact of human services community-based organizations (CBOs), and the need to strengthen and ensure their pivotal role in the larger human services ecosystem, which is comprised of an integrated web of public health and human services agencies, other public sector agencies, human services CBOs, philanthropic organizations, academic institutions, and the business community.” While CBOs provide vital services to their communities, they are often unable to provide services to the extent that they would need due to key structural factors, including the following: “public perception, operational shortcomings, financial stress, and capacity limitations.” Of these factors, financial stress and capacity limits are major contributors to a lack of sustainability in community-based efforts, poor job satisfaction for employees, and the inability to offer the volume of services a community might need.

The report found that, approximately half of CBOs are consistently operating at the deficit for a variety of reasons, including government contracts that do not fully reimburse them for the services they provide. Moreover, almost a third of CBOs have financial reserves that cover more than a month of operating expenses, which places them in an exceptionally vulnerable state if any variation or fluctuation occurs in either their costs or short term revenue. Financial instability and chronic underfunding leaves CBOs in an unfair and unstable position in which they are not fully compensated for the programs they deliver and often create stop-gaps for their financial needs through short-term grant funding, which is often non-renewable. This places an enormous burden on CBOs to keep their doors open, even as the need for their services has grown, particularly during the Covid-19 pandemic.
been funds awarded to CBOs specifically for COVID-19 relief efforts (e.g. the $66.5 million allotted to community-based outreach efforts within the American Rescue Plan), these funds are earmarked for specific programs that respond to needs that have arisen due to the COVID-19 pandemic and are only provided for specific periods of time (i.e. are not permanent additional funds that would add to the continuous operating budget of these CBOs past the timeframe for which they were awarded). Because these funds are time-limited, they do not solve the issue of ongoing financial support needed to provide continuous care and hire permanent staff. This short-term, uncertain funding strategy perpetuates a funding environment for CBOs that leaves them in precarious financial situations if they are unable to procure additional funding after their initial funds have been spent.543

Specific to the Peripartum Period, community-based programs such as the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), which provides supplemental food support, breastfeeding support and education, nutritional education, and linkage to other social services, have been shown to positively impact infant health outcomes, breastfeeding continuation rates, utilization of other health services, and overall nutrition of new families.544 WIC in particular has also been shown to significantly reduce healthcare costs associated with preterm birth and other poor infant health conditions.545 Moreover, community-based care has also been shown to increase healthcare utilization and decrease disparate birth health outcomes.546

By recognizing the unique role that CBOs can play in improving the health of communities through addressing social determinants of health and providing care in a more mobile manner than traditional healthcare delivery methods and incorporating CBOs into reimbursement strategies, health plans can contribute to a vital restructuring in the way CBOs are
funded, ensuring both their continuity as a resource to their community and more equitable reimbursement for community-based workers. As discussed in Chapter Three of this dissertation, the role of CBOs is especially crucial in the postpartum period, and should be incorporated into how we think about our efforts to expand postpartum Medicaid coverage.

b. An Ethical Argument for Expanding Coverage in the Peripartum Period

Over the past two years, advocacy efforts have been growing to expand Medicaid coverage to a full year postpartum. The 2021 American Rescue Plan Act included a new option for states to expand their postpartum coverage for a full 12 months postpartum. Prior to this, Medicaid coverage of postpartum individuals was only active for up to 60 days postpartum, resulting in many postpartum individuals losing their coverage at a time when they often need additional medical support. While many states have worked to implement Medicaid postpartum expansion, there are still outliers. This subsection will briefly review why it is necessary to extend Medicaid postpartum coverage and the necessity to extend this coverage to all postpartum individuals in this country, including those with undocumented immigration status.

Medicaid has a vital role to play in improving health in the postpartum period not only because they are the largest payer of maternity care in the US, with 42% of all births being covered by Medicaid, but also because they insure a substantially higher number of patients who belong to patient populations with high rates of pregnancy complications. Historically, Medicaid has been required on the federal level to cover pregnant individuals who are otherwise ineligible for Medicaid coverage through 60 days postpartum. After 60 days, postpartum individuals lose their eligibility and are required to find coverage through another payer. This structure has contributed to negative health outcomes for postpartum patients because many
health conditions that are associated with the postpartum period such as postpartum depression, complications of high blood pressure or diabetes often do not present themselves during the first 60 days postpartum. In the case of postpartum depression in particular, signs and symptoms most commonly occur between 1-3 weeks postpartum, with a full third of the window of time in which symptoms might appear falling outside the 60 day postpartum coverage.\textsuperscript{549} Many people have found themselves in desperate situations in which their health conditions have grown substantially worse right at the moment that insurance coverage is withdrawn, leaving new families in dire health, financial burden, and in some cases, afraid or unwilling to seek necessary medical treatment or take prescribed medications to treat health conditions due to the cost of that treatment.

Several states have already begun the process of pursuing extending postpartum Medicaid coverage to a full 12 months after delivery, but there are also states that have either opted to not pursue this option or have yet to announce their plans to adopt or dismiss this move. It is estimated that if all states opted to adopt the postpartum extension, “the proportion of Medicaid patients who would retain eligibility for the full year postpartum would increase for 52\% to 100\%: an increase of approximately 720,000 patients per year.”\textsuperscript{550} This could drastically impact the lives of families and improve access to care. When thinking about Medicaid postpartum expansion, however, it is also important to consider how vital Medicaid coverage is for patients with undocumented immigration status. As Nancy Berlinger has argued, the current ineligibility for Medicaid during pregnancy and the postpartum period for undocumented individuals in some states and the ambiguity regarding eligibility status in some states has resulted in various unstandardized workarounds from providers to help their patients receive care; most frequently by sending patients to emergency departments for routine prenatal and
postpartum care because emergency visits by undocumented immigrants are covered under the Emergency Medical Treatment and Active Labor Act (EMTALA). Doing so not only deprives the patient of continuous, appropriate care, but also places an unnecessary strain on the system in the following ways: price, volume and burden. From a human rights/ethical and financial perspective, extending Medicaid coverage to pregnant and postpartum undocumented individuals is a necessity.

Conclusion

If we are to successfully build systems of care that can tend to the needs of our families and communities, we need to have ways of paying for this care that not only enables quality and equitable treatment, but encourages it. By focusing on reimbursement strategies that are fueled by the needs and values of patients and by ensuring that all pregnant and postpartum individuals have access to quality health insurance, systems of care can help new families instead of inflicting harm upon them.

5b. Exploring the Role of Quality Measurement in the Fight for Health Equity in Maternal Health

Introduction

Quality Improvement (QI) has become an integral part of efforts to improve and standardize care across various healthcare settings, but particularly in hospitals and ambulatory settings. In the decades following the “To Err Is Human” report, QI methodologies have been used to identify areas of opportunity for improvement, develop standardized workflows to
address those opportunities, and eliminate aspects of current practices that lead to preventable harm and deaths. In the context of maternal health, QI efforts have historically been lacking. However, in recent years, there has been an increased interest in considering how to employ QI to improve the practices of healthcare teams and support the health of pregnant, laboring, and postpartum patients.

I. The Essential Role of Quality Measurement in Ensuring Competence and Improving Care

To understand the role that quality improvement and quality measurement might play in improving maternal health outcomes, we must first understand its role in ensuring competence in clinical care.

a. Quality Measurement and Competence

To understand the importance of quality measurement in ensuring competence, we must first understand the role of quality measurement within Quality Improvement (QI). While there are many different approaches and schools of thought about how to best do QI, for the purposes of this chapter and our discussion, we will use the broad definition of QI as, “securing understanding of the complex healthcare environment; applying a systematic approach to problem solving; designing, testing and implementing changes using real-time measurement for improvement; and making a difference to patients by improving safety, effectiveness and experience of care.” By using a standardized approach to problem solving as well as standardizing processes related to patient care, QI methodologies and QI initiatives within
hospital settings aim to ensure fewer mistakes and more consistent implementation of established best practices with minimal to no deviation from the established standard.\textsuperscript{554}

In order to achieve optimal standardized workflows, teams involved in QI initiatives undergo cycles of continuous improvement. The most well-known model of continuous improvement is called Plan-Do-Study-Act (PDSA). Within this model, teams plan to implement one change to their current process, test out that proposed change for a specific period of time, monitor the effect their change has had on their practices and patient care, and then act on what they have learned from implementing and observing that change.\textsuperscript{555} This cyclical, methodical approach is applied continuously until the processes the team have been looking to update and improve have reached their desired state and then are monitored for fidelity and sustainability of improvements achieved.

As one might be able to glean from even the short description just given of the continuous cycle of improvement, quality measurement plays a vital role in the QI process. When designing a QI project, one first needs to determine not only what they are seeking to improve, but, just as significantly, how they will know whether or not improvements are being made.\textsuperscript{556} When studying the implementation of an iterative change, understanding how it is impacting your patients typically is done by collecting and analyzing quality measures that are meaningful to your project. For example, a quality measure that is included in every QI project to improve the time to treatment for severe hypertension in pregnancy is the number of patients who received treatment within one hour of two consecutive elevated blood pressure readings out of the total number of patients who had two consecutive elevated blood pressure readings.\textsuperscript{557} This quality measure is clearly an indication of whether or not improvement efforts are effective because it tracks what percentage of patients are receiving their medication in a timely manner.
and whether or not that percentage is increasing as changes are being implemented. Quality measurement is a cornerstone of QI because the selection of quality measures determines what you have identified as significant and worthy of determining the success or failures of your efforts. As we will see in subsequent sections of this chapter, in many cases QI efforts have been unsuccessful and have reflected bias because of the quality measures selected.

In many ways, one might consider QI the practice of improving the competence of healthcare teams, when competence is taken in Tronto’s definition of “the direct meeting of needs of care.” When one seeks to improve the processes through which care is delivered, that process of continuous improvement is, in fact, a process of modifying, assessing, and improving the ability of a healthcare team to directly meet the needs of their patients without error or unnecessary burden— in other words, a process of improving competence. So in this way, quality measurement is also a foundational component of competency, as the selection of quality measures identifies how we are determining whether or not our care is competent. When considering this relationship within the broader ethics of care approach we have been discussing throughout this dissertation, the selection of quality measurement becomes much more nuanced than one would initially think it might be. As we will see in subsequent sections of this chapter, the question of who gets to determine what we measure and how we respond to quality measurement becomes a dialogical interpretive process in and of itself once we understand that quality measurement is the driver of our efforts to improve the competency of our care.
b. The History of Quality Measurement Efforts in the Maternal Health Space

As was discussed in Chapter 3 of this dissertation, a recent growing force in efforts to implement QI efforts in the maternal health space are statewide Perinatal Quality Collaboratives (PQCs). However, there are other approaches outside of the PQC model that we should consider in order to more fully understand both the history of maternal health QI and its complicated present. In the early 2000s, the CDC discovered both that maternal mortality rates had been steadily climbing in the United States over recent decades and also that the current data gathered regarding maternal mortality was not optimal and was likely missing additional pregnancy-associated deaths. As a result of these findings, various approaches to addressing maternal mortality arose: state Maternal Mortality Review Committees, efforts to update the collection and submission of maternal mortality data, and the creation of PQCs were three central approaches endorsed by the federal government. Approximately 98% of births in the United States occur in hospitals, which is why the hospital-centered PQC model initially gained steam after California saw success in reducing its maternal mortality rates as a state in tandem with statewide hospital QI initiatives.

However, as states sought to focus on improvement opportunities within hospitals, other organizations have focused on alternative models of care and both their efficacy and ways in which they might be improved. The most notable of these alternative approaches is the midwifery approach to care, which can occur in a hospital setting if there is a midwife practicing at the hospital, but often occurs in community-based birthing centers. The Centers for Medicare and Medicaid Services Strong Start for Mothers and Newborns Initiative in 2018, for example, found that patients who gave birth with the care of a midwife in freestanding birth centers had significantly improved health outcomes to those giving birth in hospitals. There have also
been significant studies that report the improved health outcomes of new mothers when giving birth with the support of a doula in community settings and various pilots have explored the ways in which peer support and other community-centered resources result in improved maternal health outcomes.565

As a result of the federal and statewide laser focus on hospital-based PQCs to drive QI efforts in the maternal health space and the more localized pilots and explorations of alternative methods to improving health outcomes, a parallel process of attempting to improve care has been taking place. As Main notes, PQCs in certain states (most notably California) have been able to make marked improvements in regards to specific caring processes.566 However in states other than California, the work of PQCs has not clearly been shown to significantly reduce maternal mortality rates in any substantial way. This could in part be because many states’ PQCs initially focused exclusively or primarily on newborn health and not maternal health.567 But this could in part also be due to the way in which states structure their hospital-based initiatives, how they prioritize which areas of improvement they should focus on, and how they are measuring their “success” as an initiative. As Mishka Terplan has noted, and as we will explore in subsequent sections of this chapter, PQCs have largely up until this point failed to reduce racial and ethnic disparate outcomes through their initiatives, in part because of the information they choose to value and guide their work.568

While hospitals have looked to their hospital peers for education and inspiration around what has helped to improve care of pregnant and postpartum patients, they should be looking to healthcare professionals other than OB-GYNs, MFM, and hospital-based nurses and to organizations providing maternal and infant healthcare, such as birth centers, as well. As noted, midwives, doulas, community-based health workers, and peer support specialists have all been
involved in research around improving health outcomes and have conducted QI initiatives of their own to determine what will help better support the families they serve. However, as we will see, the quality measures that they center in their work are often much more patient experience-centered than the measures found in hospital QI initiatives, and often include elements such as qualitative data. By centering and incorporating a collaborative determination of what constitutes improvements, patients not only report feeling more respected and autonomous during their delivery, but also have improved health outcomes. If hospitals and even PQC are to actually make a dent in improving maternal health outcomes and reducing maternal mortality rates, they need to begin to listen and learn from their community-based counterparts and their patients, and they need to extend their scope beyond that of the inpatient hospital setting.

II. Quality and Safety

Now that we have broadly discussed QI and quality measurement in the maternal health space, we can proceed to examine the way in which safety has been conceptualized within QI and quality measurement strategies.

a. Quality Care is Safe Care: Examining the Role of Safety in Approaches to Quality Measurement

In some ways, the importance of safety to quality measurement strategies is straightforward: safety is foundational to quality. Care cannot be said to be good care if it is not also safe care. The fact that QI initiatives are typically framed as “patient safety” initiatives is a testament to this relationship. In the specific example of the maternal health space, the Alliance for Innovation in Maternal Health (AIM) names the guiding documents for its QI initiatives
“Patient Safety Bundles” to highlight the fact that QI is undergone explicitly to improve patient safety. However, because QI methods have traditionally been centered on improving patient safety in the sense defined by the “To Err Is Human” report—namely, as efforts to reduce preventable error and patient death—the quality measures selected to inform and drive QI efforts often reflect the negative conception of safety they seek to improve.

To illustrate other possibilities for quality measurement, we will now turn to Porter’s Outcome Hierarchy (2010), showing how there are multiple layers of outcomes that are valued to differing degrees by patients that need to be incorporated into how we measure quality.

According to Porter’s analysis, the poor state of QI efforts in the United States is due to lack of consensus about which outcome measures we should use to monitor and determine progress and ultimately success. According to Porter, “There is no consensus on what constitutes an outcome, and the distinction among care processes, biologic indictors and outcomes remains unclear in practice.” Moreover, the kind of outcomes that are traditionally considered in QI are short-term outcomes that reflect immediate receipt of specific procedures or treatment and not, as they should be, the “overall success of the full care cycle for medical conditions.” To briefly return to an example I invoked earlier in this chapter: when hospitals focus on the number of patients that receive their blood pressure medication within one hour of two consecutive high blood pressure readings, this is a focus on an immediate outcome/measuring the receipt of a specific treatment and would fall into the type of traditional outcome to which Porter is referring. This model of measurement is the result of healthcare providers only wanting to measure what they have direct control over and the services that they specifically provide, rather than the overall health outcomes that matter to patients.
In alternative to the traditional conception of outcome measures, Porter proposes an outcome measure hierarchy that can be used as a tool to determine which outcomes should be prioritized when determining whether or not care has been successful or has improved. For the specific condition or patient population that is being considered, the following four principles should be considered: “1) outcomes measured should involve health considerations most relevant to patients; 2) outcomes should include both near-term and long-term health in order to ensure that the full results of care are included; 3) Outcomes need to cover the full range of services that are involved in the patient’s care and help determine their health; and 4) measurement needs to also include measure of risk factors or factors that would allow for risk adjustment.”

For the purposes of this chapter, there is neither time nor the need to do a deeper analysis of some of the nuances of Porter’s hierarchy. However, most relevant to this discussion is Porter’s hierarchy are the three tiers he identifies within this hierarchy, each of which have different levels. Tier 1 is “patient health status achieved” and the degree of health or recovery achieved, Tier 2 focuses on the process of recovery, including the time it takes one to recover and the impact that recovery (and failures of care during recovery) can have on quality of life, and Tier 3 focuses on health outcomes over time, including both the extent to which health status achieved by care is sustained but also whether or not the care one received cause additional health problems in the patient. This hierarchy presents us with a much more robust analysis of patient health than a framework that focuses primarily process measures such as whether or not a patient was given their medication during an appropriate window of time. By adopting the hierarchy of outcomes, quality is measured through a more holistic, nuanced framework that takes into account the health and desires of the patient rather than merely what the individual provider believes he has control over.
Adopting this hierarchy also helps to redefine how we conceive of outcomes themselves in a way that is more substantive and patient-centered in nature. While traditional QI initiatives would consider outcomes more focused on satisfaction of care received, this framework has as its overarching goal and orienting force a focus on satisfaction of overall health. As Porter states, “Patient satisfaction with care is a process measure, not an outcome. Patient satisfaction with health is an outcome measure.”578 This reframing inherently changes the structure of quality measurement itself and also opens the door to a more robust engagement with patient voice in quality measurement efforts.

b. Who Decides the Quality of Care? Patient Voice in Approaches to Quality Measurement

While Porter provides a crucial component in understanding how quality measurement can better be defined in order to improve QI efforts, there is another component of quality measurement that needs to explicitly be centered in order to make the types of meaningful movement forward in the QI space: patient voice. With that in mind, we will now turn to the Birth Place Lab’s work on redesigning quality measures in maternal health, showing how quality care should be “tailored to individuals, weighs benefits and harms, is person-centered, works across the whole continuum of care, advances equity, and is informed by evidence, including cost-effectiveness.”579

As quality improvement has become an integral part of healthcare delivery in the US, there have been various attempts to try to incorporate patient voice into QI efforts, to various degrees of success.580 In Committee Opinion no. 490, ACOG recommends that communication and partnership with patients should be incorporated into safety improvement efforts, patient involvement in the planning of health services is recommended, and, note that, “physician-
patient communication problems may account for an increase in medical professional liability actions.” Despite these recommendations, patient voice is often missing from the conversations that determine the structure of quality improvement efforts, and, as Porter noted, specifically from the conversations that determine which outcome measures are chosen to monitor and determine progress.

In a call to action in support of the United Nations/WHO “survive, thrive, and transform” agenda, a group of leading midwives in 2018 compiled a call to action to promote strategies for improving the health of birthing people and newborns, arguing that an emphasis in research and QI on reducing maternal mortality has led to a lack of research and improvement efforts focused on building the infrastructures necessary to provide supportive care. While the reduction of short term morbidities is, of course, an admirable goal, health outcomes for new parents will not improve unless if serious emphasis and funding is put on proactive approaches to improving care. In opposition to the current dominant approach of funding research and improvement efforts that are not focused on long-term health benefits, the group proposes a Quality Maternal and Newborn Care Framework, which lays out the full spectrum of care that should be accessible for maternal and newborn patients.

The Quality Maternal and Newborn Care Framework contains the following components: “Practice Categories, Organization of Care, Values, Philosophy, and Care Providers.” Within Practice Categories, characteristics such as “education, information, promotion of health, assessment, screening, care planning, promotion of normal processes, prevention of complications,” are all considered, while for Organization of Care, characteristics such as, “available, accessible, acceptable, good-quality services—adequate resources, competent workforce, continuity, services integrated across community and facilities,” are all considered.
For Values, “respect, communication, community knowledge and understanding, care tailored towards women’s circumstances and needs,” are desired characteristics of care.\textsuperscript{587} Within Philosophy, the characteristics prioritized are, “optimizing biological, psychological, social and cultural processes; strengthening women’s capabilities, expectant management, using interventions only when indicated,” and the characteristics for care providers include, “practitioners who combine clinical knowledge and skills with interpersonal and cultural competence, division of roles and responsibilities based on need, competence and resources.”\textsuperscript{588}

The Quality Maternal and Newborn Care Framework maps on quite well with Porter’s Outcomes Hierarchy due to its focus on the broader episode of pregnancy, as well as the more qualitative aspects of assessing care. However the QMNCF also contains the additional important benefit that the emphasis on patient and community input in the category of Values provides a clear avenue to explicitly include patient voices in the design and implementation of their own care. As will be discussed further in subsequent sections of this chapter, The Birth Place Lab has made considerable strides towards illustrating what patient inclusion and the centering of patient voice and experience in quality measurement might look like through their Measuring respectful maternity care tools Mothers Autonomy in Decision Making scale (MADM)\textsuperscript{589} and Mothers on Respect Index (MOR).\textsuperscript{590} Ensuring that patients are involved in the creation and evaluation of quality efforts can lead to the inclusion not only of outcomes that promote physical health, but of outcomes that traditionally have been excluded from QI efforts, such as respect for patient autonomy, perceived receipt of care, feelings of bias or stigmatization in care, etc. As we will see in the following section, the inclusion of these types of considerations will be vital if our quality efforts are to succeed in contributing to equitable care for all.
III. Quality and Equity

This section will focus on the need for equity to be centered in quality measurement and quality improvement efforts. In order to do this, and in order to design quality measures that encompass the characteristics laid out in subsection II, we need to develop and implement models of care that “enhance both well-being and safety, investigativ[e] and optimiz[e] physiological, psychological, and social processes in pregnancy, childbirth, and the postpartum period…and develop and validate outcome measures that capture short and longer term well-being” in a way in which patient voice is centered and equity is the goal.591

a. “There Is No Quality Without Equity”: Equity As a Foundational Component of Quality Care

“There is no quality without equity and there is no equity without quality,” states a 2022 article from the Journal of the American Medical Association.592 And indeed, if one has attended any of the myriad of quality improvement presentations through the course of the past five years, one may have heard the phrase “there is no quality without equity” as a preface to a discussion of quality improvement in the maternal health space. However, what does the phrase, “there is no quality without equity” actually mean when it comes to both determining quality of care and the success of quality improvement efforts? While the Institute of Health deemed Equity as one of its 6 dimensions of quality care, Reichman et al have noted that while QI is in some ways well-suited to promoting equity given its focused and stepwise approach, in practice, when a QI methodology does not have an explicit emphasis on equity, it has in practice inadvertently widened health disparities.593 Reichman et al. posit that “Equity Focused-Quality Improvement” (EF-QI), as defined as “QI initiatives that integrate equity throughout the fabric of the project
and are inclusive, collaborative efforts that prioritize and address the needs of disadvantaged populations” is an action oriented and equity-centered approach to ensuring the equity is a centralized component of QI efforts.\textsuperscript{594} By framing QI efforts through the lens of what actions would most improve the care for patients whose health outcomes are currently the worst, the resulting care will be better for all.

There have been several strategies proposed to incorporate an equity focus into QI work. One strategy is that of creating and maintaining a “disparities dashboard” that tracks outcomes by relevant demographics (including race and ethnicity) that will inform one’s work.\textsuperscript{595} Other scholars have advocated for assessing for structural racism and bias on the organization level that may be informing disparate health outcomes.\textsuperscript{596} However, Dzau et al. note that health systems largely do not currently have the infrastructure to “center and build equity” but are capable of building upon their existing infrastructures to “measure, monitor, improve, and incentivize quality to also build a more equitable health system by focusing on 3 areas: data, leadership and governance, and payment.”\textsuperscript{597} This broader systems approach has been illustrated to have merits in practice by the work of Elizabeth Howell et al, who performed an investigation into high-performing versus low-performing hospitals when considering racial and ethnic disparities on Labor & Delivery. According to their findings, high-performing hospitals had the following in place: “1) senior leadership involved in day-to-day quality activities and dedicated to quality improvement, 2) a strong focus on standards and standardized care, 3) strong nurse-physician communication and teamwork, 4) adequate physician and nurse staffing and supervision, 5) sharing of performance data with nurses and other frontline clinicians, and 6) explicit awareness that racial and ethnic disparities exist and that racism and bias in the hospital can lead to differential treatment.”\textsuperscript{598}
In order for teams to be successful in delivering equitable care, they not only have to be aware of racism and bias and how it might present itself, but they also need buy-in from organizational leadership, a strong team, and a focus on standardization of care. These elements for success reflect an additional study that found that racism and discrimination on L&D contributed to disparate outcomes in the following ways: 1) care segregation, 2) care variation, 3) communication and cultural humility; and 4) structural racism and policy.\textsuperscript{599} Because disparities in care are caused by different factors at different levels of the organization, the centering of equity in improvement efforts needs to be present on all levels of the organization as well as reflected in organizational policies.

In recent years, Joia Crear-Perry, MD, FACOG, the Founder and President of the National Birth Equity Collaborative, has emphasized the need for what she has termed birth equity: “the assurance of the conditions of optimal births for all people with a willingness to address racial and social inequities in a sustained effort.”\textsuperscript{600} The creation of Birth Equity as a category of equity is significant for the perinatal space, because it entails adopting an explicitly equity-focused, anti-racist approach to QI with the specific context of childbirth in mind, and can therefore serve as a conceptual anchor for QI efforts within the perinatal space.\textsuperscript{601} A restructuring of our QI efforts to center a foundation of equity is desperately needed in the maternal health space. The following subsection will explore potential pathways to pursue this restructuring from leading Black Reproductive Justice scholars in this space.

\textbf{b. Who Decides What We Measure? Redesigning Quality Measurement Strategy}

Black Reproductive Justice scholars have argued in recent years that a restructuring of improvement efforts in the maternal child health space needs to take place in order to center
those most impacted by disrespectful care and disparities in an actionable way. In “The Cycle to Respectful Care,” scholars have posited an approach in which core values are established as the center of cycles of improvement and a process of co-creation unfolds. The core values of the Cycle include: valuing patients’ “Black Intersectionality,” “Birth Equity,” “Reproductive Justice,” the “Professional Pledge/Oath” healthcare professionals take when beginning their careers, “Holistic Maternity Care,” “Humanity,” and “Love of self and others.”

These core values were created through dialogue with communities, Community-Based Organizations, and hospital staff, and each step of the process laid out in the cycle was also co-created in dialogue with community. As a result, the cycle from start to finish both incorporates the perspective of the lived experience of Black birthing people and incorporates qualitative components that hold value for patients in its determination of proposed changes, processes and identified measures. We will revisit this cycle in the following section, but for now, it is enough to note that the Cycle of Respectful Care entails a wholly collaborative process in which shared decision making is incorporated and centered.

Dr. Karen Scott has also posited a framework through which to redesign QI initiatives and patient research she calls “Participatory Quality Improvement Research” (QIR). The strength of this model is that it, “shifts the power of knowledge construction from QI experts to a community of Black mothers and birthing people, in established equitable and dignified partnerships with Black women scholars.” This shift of power is accomplished through the following steps: “1) name the phenomenon that best captures the personal lived experiences and conditions of birthing in hospitals from the detailed individual and collective perspectives, voices, and words of Black mothers and birthing people; 2) define the phenomenon and provide meaning that is unique to the complex and oppressive and emancipatory birth expectations and
experiences of birthing while Black in hospitals; 3) measure, examine, and modify the phenomenon using research justice methodologies for social change.\textsuperscript{605}

QIR also restructures the QI structure by placing an explicit emphasis on the importance of organizational leadership buy-in and pre-implementation activities that center building cultures of equity and anti-racism that must take place for co-creation with Black communities to be successful. In order for community voices to be heard in conversations regarding lived experience and how that experience can impact health outcomes, the healthcare teams must first be in a position to listen to and respect their community partners. This importance of this pre-implementation work cannot be understated, as a lack of preparation on the part of hospital teams has been the downfall of many attempts to partner with patients and communities in improvement efforts.\textsuperscript{606}

In summary, while Porter expanded our scope of what outcomes we should measure to include a wider range of long-term health considerations that reflect what matters to most patients, Black scholars in the maternal child health space have emphasized that in order to make substantive changes in addressing the vast racial and ethnic disparities in maternal health, Black patients and Black communities need to be co-creators in QI efforts, including co-determiners of which quality measures will be selected to help drive and assess progress being made. Because patient and community involvement in quality measurement has been established as an integral part of striving for equitable health outcomes in the maternal health space, we will now discuss a significant component of patient participation in QI efforts: qualitative data and the role of patient narratives in quality measurement.
IV. Qualitative Data and the Role of Patient Narratives in Quality Measurement

As we move to more collaborative models of QI and quality measurement, we must begin to understand the role that qualitative data and patient narratives can play in improving quality of care.

a. The Necessity of Collecting and Analyzing Qualitative Data in Maternal Health

As stated in “The State of Black Women & Reproductive Justice Policy Report,” the continued failure of our healthcare systems to provide adequate or quality care for Black birthing people is in large part a result of healthcare teams and health systems not listening to the needs of Black pregnant and postpartum patients. Moreover, in “The Ethics of Perinatal Care for Black Women,” the following 8 ethical standards are posited as mandatory competencies for healthcare teams to possess:

1) Listen to black women;
2) Recognize the historical experiences and expertise of black women and families;
3) Provide care through a reproductive justice framework;
4) Disentangle care practices from the racist beliefs in modern medicine;
5) Replace white supremacy and patriarchy with a new care model;
6) Empower all patients with health literacy and autonomy;
7) Empower and invest in paraprofessionals; and
8) Recognize that access does not equal quality care

These ethical standards and the statements of the policy report highlight that because a large part of the root of why care has been substandard for women of color and for Black women in particular is because their voice has been ignored in their own care, inclusion and amplification of their voice and their perceptions of their own care must be a central and foundational element of improvement efforts.
In contrast to traditional QI projects that utilize quantitative data to determine their benchmarks for measurements and their progress towards success, QI efforts in the maternal health space in particular need to include qualitative data collecting patients’ perception of the care they receive because the success of that care is in many ways directly tied to their receipt of it. Qualitative data also helps to determine to what degree the intervention implemented is actually helpful in making the proposed improvement. For example, QI efforts to improve the identification of and care for pregnant individuals with Substance Use Disorders (SUD) in recent years have typically included tracking how many individuals receive screening with a validated SUD verbal screening tool. Typically the success or failure of this intervention is measured by whether or not the percentage of patients screened goes up or down over time. However, an essential component of whether or not an SUD verbal screening is successful is the way in which the screening questions were asked. Were the questions asked dismissively, leaving the patient reticent to answer in the affirmative for fear of judgment? Were the questions asked with judgment or malice? Did the individual bias of the provider inform the manner in which the questions were asked? All of these considerations influence whether or not a patient feels safe enough to disclose use in response to the screening.

In order to know the full extent of whether or not improvement efforts have been successful requires feedback from the individuals receiving the updated caring processes. If quality measurement and QI processes are the means through which we make our care more competent, we cannot know that we have succeeded unless we engage in a dialogical interpretive process with those receiving the care. While quantitative data is an important component of measuring specific aspects of improvement, without incorporating qualitative data into our
understanding of where we are and where we need to go, we will always fall short of our mark. 

b. Data Are a Beginning, Not an End: The Role of Patient Narratives in Quality Measurement

In considering the causes of severe maternal morbidity and maternal mortality, the prevalence of “nonadherence to treatment” and “failure to obtain medical care” need to be understood through the context of the words presented in these accounts of mistreatment experienced by individuals during their experiences with healthcare teams. While individual patients’ accounts of experience of mistreatment may echo the findings of the Birth Place Lab’s “Giving Voice to Mothers” study in articulating the types of mistreatment experienced, reading or hearing the words of an individual is a different experience from reading a list of ways in which care has failed patients.

In November 2019, I was fortunate enough to hear Charles Johnson speak at the Illinois Perinatal Quality Collaborative annual conference about his wife Kira and their experience of neglect that led to her death. As Mr. Johnson told his story, every healthcare professional in that room was clearly moved; when he repeated the words that his wife’s nurse spoke to him: “Your wife is simply not a priority at this time,” one could hear nurses gasping in shock. Attendees cried in outrage and sorrow during his presentation and in the following sessions of the day Mr. Johnson and his story were frequently cited as calls to action. I reflect on this experience often as I have continued working with hospital teams to improve care for pregnant and postpartum individuals. During the past three years, I have often been told by nursing and departmental leaders that efforts to improve care for pregnant individuals with Substance Use Disorders is “not
a current priority,” despite this patient population growing as the effects of the Covid-19 pandemic persist. In an environment in which teams are juggling multiple priorities and multiple responsibilities, it is easy for them to lose sight of the immense importance of working to improve the health and lives of their patients in meaningful ways.

Patient narratives are an essential component of quality improvement and quality measurement because they both highlight the urgency of the need to improve but also help healthcare teams understand more fully the types of improvement that need to be made. While disparities dashboards and safety checklists are important tools in improving care, the voice of patients who have experienced sub-par care as a result of the current practices of healthcare teams need to be incorporated into the process of continuous improvement because without them, the true consequences of our failure to improve will not be fully felt.

Moreover, patient accounts of aspects of their care that they found supportive and excellent can serve as part of a roadmap to building proactive, positive caring experiences. Centering patient voice in quality improvement efforts also allows for more robust discussion of the type of care patients would like to see more of and to describe the behavior they appreciated during the time they received care. By asking patients questions about what they need to feel supported and what behaviors help to build trust with their care team, improvement efforts can be driven both by what has not been working and by amplifying and expanding upon what has been working.

Charon’s notion of narrative competence that we discussed in Chapter Two of this dissertation is a relevant consideration when considering why and how patient voice might enrich and empower our improvement efforts. Charon notes that when healthcare providers develop narrative competence, they, “can become more attentive to patients, more attuned to
patients’ experiences, more reflective in their own practice, and more accurate in interpreting the stories patients tell of illness.” The inclusion of patient voice in improvement efforts entails a dialogical-interpretive development of narrative competency that can both strengthen care teams’ ability to create more caring environment by providing the team with more experience in hearing, interpreting, and responding to, patient stories. Charon notes that, “if patients’ reports do not limit themselves to answers in our reviews of systems, then we must be prepared to comprehend all that is contained in the patient’s word, silences, metaphors, genres, and allusions. Listening and watchful clinicians must become fluent in the tongues of the body and the tongues of the self, aware that the body and the self keep secrets from one another, can misread one another, and can be incomprehensible to one another without a skilled and deft translator.”

Our current systems of care in maternal health have been constructed in large part through not listening to the voices of women and by ignoring their needs. Engaging patient voices and patient narratives in improvement efforts ensures that listening is the first step to understanding how to build better systems. And through prioritizing listening itself, rather than current system, there is the potential to build a better, more responsive system that will care for patients in all of their dimensions.

V. The Role of Quality Measurement in the Fight for Health Equity

In order to understand the structural factors that can inform how to design quality measures around longer term health outcomes for the mother-infant dyad, the final section of this chapter will return to the importance of Social Determinants of Health (SDOH) and ways in which data collection and QI can be integrated into the caring process.
a. Social Determinants of Health and the Move from Disparity-Focused Measurement to Health Inequity-Focused Measurement

The previous sections of chapter 5b have considered the structure of quality measure design, process improvement, and the ways in which qualitative data and patient voice need to be incorporated into QI efforts that center equity. We will now pivot back to a wider, structural lens regarding social determinants of health and their impact on care and how we measure quality of care. ACOG and AIM have argued for Social Determinants Of Health (SDOH) screening and support services in maternal care but often these services are not standardized or reimbursed by health insurers. Designing quality measures that would accurately reflect the priorities and needs of the mother-infant dyad would provide an argument for reimbursing these services as a part of a bundled payment, and would also lead to more just health outcomes.

In order to move the work of equitable process improvement forward, Bryant-Mantha has argued that we need to move from a disparities-focused strategy of quality measurement to a health inequity-focused system of measurement. Disparity, which can be defined as “the quantity that separates a group from a reference point on a particular measure of health that is expressed in terms of a rate, proportion, mean, or some other quantitative measure,” can be a limiting place from which to start out inquiry into health outcomes and outcomes improvement because it merely states a difference in numerical value between one group versus others without any interrogation into that difference. In contrast, Health Inequity, which is defined by the Boston Health Commission as “difference in health that is not only unnecessary and avoidable but, in addition, are considered unfair and unjust” and leave specific populations more vulnerable to poor health than others due to social injustices, already incorporates a wider lens through which to understand the underlying cause of disparities, as well as their preventable nature.
Shifting our focus from disparities-driven work to health inequity-driven work allows us to more explicitly incorporate a consideration of SDOH into our efforts to improve longterm health outcomes for the dyad. One way in which this lens has already been adopted and explored is through the Ariadne Lab’s Maternal Wellbeing City Dashboards, which were created through the Merck for Moms A Safer Childbirth City initiative. These dashboards map out key social determinants for maternal and newborn health at the city and neighborhood level and track how they influence health outcomes over time. The determinants included in the dashboards are: “1) Health and Attainable Housing; 2) Reliable and Affordable Transit Systems; 3) Safe Water, Air, and Open Spaces; 4) Nourishing Food Systems; 5) Equitable Education and Jobs; 6) Person-Centered and Dignified Healthcare; 7) Connected and Cohesive Communities; 8) Anti-racist Neighborhood Security.” Through contextualizing healthcare services within their broader social and economic conditions, the Maternal Wellbeing City Dashboards provide a structure through which we can understand how quality measurement in a healthcare setting can be linked to broader systems of care that either support or harm the health of pregnant and postpartum individuals.

Just as patient voice is an integral part of understanding where we are and how we need to improve, incorporating social and economic structural factors into our improvement efforts via an inequities approach to measurement is another necessary component in moving towards more meaningful measurement and more equitable, quality care.

b. Integrating Data Collection and Quality Improvement into the Caring Process

Health inequities are found across almost every component of healthcare, and are informed by health system factors, provider factors, patient-level factors, clinical encounters, and
structural factors.\textsuperscript{624} Due to factors such as implicit bias of providers, women of color face disparate and unjust treatment across all phases of reproductive health and the lifespan.\textsuperscript{625,626,627} In order to address issues of inequity, we first need to accurately measure the inequities that currently exist, as well as our responses to those inequities. In order to do so, Massachusetts General Hospital suggests that the following data should be collected: Race, Ethnicity, Socio-Economic Status, Language Preference, Sexual Orientation/Gender Identity, Social Determinants of Health, and Experience with Discrimination (as well as any outcomes that are of value to the specific organization).\textsuperscript{628}

When taking these suggestions from Massachusetts General into consideration in the context of the previous sections of this chapter, it is clear that an equitable measurement strategy is one that clearly identifies current inequities, engages with patients and communities that are experiencing those inequities, and creates quality measures and benchmarks to illustrate progress in collaboration with patients and communities. This strategy differs from the current mainstream QI processes that hospitals engage in because it requires a large portion of the data collected in measuring current health inequity outcomes to be self-reported and typically requires follow-up with the patient in order to glean meaning from one’s findings. This means that as organizations gather information about the way in which their patients are currently being treated, they will also have to engage in a dialogical-interpretive process in order to understand the cause of any disparate treatment and the effect that this treatment has had on the patient. In this way, data collection and the quality improvement efforts that are formed as a result of that data collection can be integrated into the caring process itself, and can provide another means through which providers, patients and organizations can work together to provide better care and more equitable care.
Conclusion

It is often said in QI work that “data tell a story.” While this is certainly true, the story that is told is greatly impacted by which data are selected as the story tellers and whose translation of the story we adopt. To build systems of care that contribute to the flourishing of pregnant and postpartum individuals, their families, and their communities, we not only need systems of payment that encourage competent care, but systems of improvement and quality measurement that center the voices and needs of patients, particularly those whose voices have historically and contemporarily been ignored. Inequitable health outcomes and inadequate care will not cease to persist unless and until we redesign and co-create proactive systems that tend to the health and flourishing of families and communities. This will require a broadening of our scope and definitions of quality improvement work to include the social and economic contexts that influence the health and wellbeing of families and communities.
Chapter Six: Safety and Responsiveness

There is never time in the future in which we will work out our salvation. The challenge is in the moment; the time is always now

- James Baldwin

6a. Expanding Plans of Safe Care for the Mother-Infant Dyad: An Ethics of Care

Approach

Introduction

In attempting to address the complex social and medical needs of pregnant and postpartum individuals experiencing Substance Use Disorders (SUD) and their children, efforts have been made federally, statewide, and county-wide across the United States to provide wrap around support via Plans of Safe Care. As of 2022, when this chapter was written, the formal terminology for these plans is “Plans of Safe Care” but there are current efforts on the federal level to modify this terminology to “Family Care Plans”. Because Plans of Safe Care is the term currently utilized in legislation and colloquially, I will continue to use this term throughout this chapter and dissertation, but it is important to note that this terminology will soon be outdated. This section explores the Plans of Safe Care framework and the extent to which it is sufficiently responsive to the needs of mother-baby dyads.

I. Safety and Responsiveness

Responsiveness is a crucial component to providing care within an ethics of care framework, and is a central concept to making strides towards more equitable and safe care,
particularly in the maternal/child health space. To understand the extent to which responsiveness is key to our caring efforts, we must first understand its significance within an ethics of care.

a. The Role of Responsiveness in an Ethics of Care

Tronto designates Responsiveness as the fourth phase of caring, which can, in simplest terms, require that when we approach the question of how to care we “consider the other’s position as that other expresses it” as opposed to asking ourselves what we would want if we were in a similar situation to the individual for whom we are caring. Responsiveness is crucial to an ethics of care because it acknowledges that the context in which care is received, as well as how the caring acts are received by the individual, greatly influences the success of the care offered. Because individuals inhabit different social, cultural and interpersonal identities, the type of care they might require and the way in which specific caring efforts are received may differ as a result of various power imbalances (e.g. structural racism, professional hierarchies, etc.). While the saying “put yourself in another’s shoes” might be a popular attempt to encourage kindness in children, this approach to interpersonal responsibility is inherently skewed because not all individuals experience the world in the same manner. This is what Margaret Urban Walker means when she claims, “differently placed people know different things in fact.” This requires us, in the words of Tronto, to be engaged, “from the standpoint of the other, but not simply by presuming that the other is exactly like the self.”

As also noted by Tronto, Responsiveness requires that the caring individual practice moral attentiveness. In order for the individual receiving care to receive this care well, it has to respond to their individual needs. If the full needs of the individual have not been identified, it is highly unlikely that the care that they receive will adequately address those needs. In this way,
Responsiveness and its relationship to attentiveness is what allows the caring process to be an ongoing, collaborative effort that does not end when the caring acts themselves have concluded, but when the extent to which the care has been received and considered successful by the recipient of care has been established. This response to care is essential because it establishes morality as, “a socially embodied medium of mutual understanding and negotiation between people over their responsibility for things open to human care and response.”634 Responsiveness is also the phase in which the dialogical-interpretive (or in Walker’s terms, the “expressive-collaborative”) aspect of an ethics of care approach can be seen. The process of determining the extent to which care has responded to the vulnerability of the individual who needs care while also recognizing and balancing the needs of the carer within this process necessitates communication, collaboration and interpretation between care-givers and care-receivers.

While responsiveness might already appear to contain an element of ambiguity, given its collaborative nature, this is even truer in the context of maternal health due to the nature of pregnancy as a health condition. As we will see in the following sections of this chapter, responsiveness in a perinatal setting presents a myriad of complexities due to the ways in which fetal and newborn health and safety have been conceptualized and weaponized, resulting in a failure to be responsive to the needs of mothers.

b. Examining the Role of Safety in Contemporary Conceptions of Responsiveness in Peripartum Health

Perinatal health is a unique context in healthcare because it is one of the only situations in which there are two patients being cared for through coordinated services. One need only to dip one’s toe into the literature surrounding perinatal health or to open a newspaper to begin to see
the various complexities that this unique situation poses for healthcare teams. In the context of
the United States in particular, conversations around patient safety are further complicated by the
ways in which healthcare has become intimately involved with, and beholden to, legal and
criminal systems. As we will learn in the following sections of this chapter, responsiveness in
perinatal health has largely been centered around the responding primarily (or in some cases
solely) to the perceived threats to the safety of the fetus or newborn, and pregnant or postpartum
mothers are often construed as a barrier to the health of the child or the sole cause of negative
health outcomes for her child, particularly if those mothers are Black.

As Rickie Solinger has noted, one of the failures of the dominant discourse surrounding
the debates regarding abortion in the late 1960s and early 1970s is the selection of the framework
of “choice” as a lens through which to understand pregnancy and the relationship one has to her
body. The popular discourse of the time framed “choices” about reproductive life in an
abstract, context-free manner that did not take into account the material and social conditions
that impact individuals’ health statuses and their actions during any period of their life, but
especially during pregnancy. The discourse surrounding debates regarding abortion dominated
overall discourse about reproductive health and the framework of “choice” was extended to other
behaviors and in some cases to health status itself. Medically, the consequences of this line of
reasoning have been illustrated through obstetric violence- the coercion and mistreatment of
women at the hands of their providers “for the good of the child”- and through obstetric racism-
which entails, in part, “how the Black female pregnant body was viewed and treated as an
incubator requiring control, surveillance, and regulation,” and leads to Black women being
disproportionately blamed for any negative health outcomes their children might have.
Legally this has led to the “criminalization of women’s conduct during pregnancy,” which has included the history of incarcerating low income pregnant women and women of color who use illicit substances during pregnancy, the denial of desired life-saving treatment such as chemotherapy due to fears of fetal harm, confining patients to hospitals via court order against their wishes to ensure bed rest is being enforced, and in the case of Christine Taylor, being charged with criminal feticide after her nurse did not believe that her accidental fall down a flight of stairs that resulted in a miscarriage was, in fact, an accident. As Michele Goodwin has argued, much of the legal discourse surrounding pregnant women “presume a life and right for embryos and fetuses apart and distinct from that of the pregnant women who bear them.”

Rather than caring for mothers and receiving them supportively in a manner that would be responsive to and promote the health of dyad, women are seen as containers for children and are punished when their actions while pregnant are perceived as incorrect or potentially threatening to their child. This has resulted in a situation in which pregnant and postpartum women are failed ethically because of the lack of responsiveness to their needs and the dehumanization that the objectification of their pregnant body entails, but has also resulted in medical practices and legal consequences that are harmful to fetal and newborn health as well.

The proportion of responsiveness to the needs of the mother-baby dyad has disproportionately concerned itself with the needs of the baby in a manner that centers perceived threats to safety rather than concrete clinical concerns. This is not to say that the needs of babies are not important. However, by neglecting and- in many cases criminalizing- pregnant and postpartum women, we have failed both members of the dyad and the health of mothers and babies has suffered as a result. The following sections will further explore the ways in which this disproportionate responsiveness and the use of perceived threats to the safety of babies to punish
and coerce women have failed the mother-baby dyad as well as potential solutions to help tip the scale in a more balanced direction and improve health outcomes for both mothers and babies.

II. Substance Use Disorder, Vulnerability, and Maternal Subjectivity

This section will explore the ways in which maternal substance use disorder has been conceptualized and treated have neglected the role of vulnerability and Adverse Childhood Experiences (ACEs) in a way that demonize pregnant and postpartum women with substance use disorders and misconstrue and negatively impact their maternal subjectivity.

a. Substance Use Disorder, Adverse Childhood Experiences, and Vulnerability

Adverse Childhood Experiences (ACEs) can be described as “potentially traumatic events that can have negative lasting effects on health and well-being. This include maltreatment and abuse as well as living in an environment that is harmful to their development.” As researchers have begun to understand the connection between ACEs and behavioral health and social challenges in adulthood, efforts have been made to assess for ACEs through surveys and assessment tools to measure how many ACEs an individual may have experienced in their childhood. According to the CDC, “61% of adults had at least one ACE and 16% of adults had 4 or more types of ACEs, with females and racial/ethnic minority groups at a greater risk for experiencing 4 or more ACEs.” A 2021 review of ACEs and SUD found both that ACEs are prevalent among people with SUD, and that there is a positive association between ACEs and a diagnosis of SUD in adulthood. When it comes to opioid use in particular, research has found that experiencing 4 or more ACEs is associated with earlier age of initiating opioid use as well as recent injection drug use and lifetime overdose.
When one considers both the impact that early experiences of trauma can have on the parasympathetic nervous system and the effect that substances such as opioids can have on the brain, the connection between ACEs and SUDs begins to make sense. When a child experiences multiple forms of trauma, the body and brain find themselves in an elevated state of distress for long periods of time. Substances that act as a depressant to the nervous system can help the body regulate itself in a manner many individuals with traumatic histories have never experienced before. While many misperceptions of substance use in the past have painted a picture of individuals with SUDs as “chasing a high”, for many individuals who develop SUDs, their substance use is not an attempt to seek a high, but an attempt to seek normalcy. To quote an example from recent popular media, in the words of Rue Bennett, the protagonist of the show *Euphoria*, on the first illicit substance she ingested: “This is the feeling I have been searching for my entire life, for as long as I could remember. Because suddenly, the world went quiet and I felt safe in my own head.” This means that in individuals who have experienced 4 or more ACEs are both vulnerable and susceptible to developing SUDs in their adulthood.

Henk ten Have writes that, historically, vulnerability has typically referred to one’s potential to be harmed, one’s diminished capacity for autonomy, or one’s fragility or weakness. However, to ten Have, the use of the term vulnerable to describe an individual or group of individuals who are at greater risk of being harmed is of great interest. This is because vulnerability in this context describes a potential: one need not actually be harmed in order to be vulnerable; the term vulnerable simply means that the potential exists. However, if vulnerability entails a relationship to potential harm, there is also the opportunity to prevent this harm. If certain individuals are at greater risk of being harmed and we can identify both the harm and the potential for risk, there is a greater potential to mitigate the risk and intervene. So while
vulnerability can be taken as a universal concept in some sense, because humans are fragile and all have the potential to be harmed, there are also specific circumstances that render a group or an individual more vulnerable to specific harms and vulnerable in ways they otherwise would not be if they existed in different economic and social conditions.653

In response to this conception of vulnerability, Kottow has argued that vulnerability in and of itself should not be considered an ethical principle, as it is merely a “descriptive feature of humanity” and does not in and of itself carry an ethical or normative significance.654 While it is appropriate to recognize that socially or medically induced states of vulnerability are different from the inherent vulnerability of humanity, it is a mistake to refer to all kinds of potential harm as vulnerability.655 A new term is needed: one that will provide both a meaningful distinction between descriptive fragility and the cases of those whose vulnerability mandates action to help prevent and alleviate harm. Kottow believes the term “susceptibility” addresses the unique situation of those whose potential for harm is beyond that of the universal human vulnerability. In contrast to the universality of vulnerability, susceptibility “is a specific and accidental condition to be diagnosed and treated.”656 Kottow argues that susceptible individuals differ from those who are vulnerable in that they have already suffered harm by being positioned in a manner in which they have been “damaged” by their circumstances.657 By damaged, Kottow means that those who should be considered susceptible are already suffering due to their precarious, often demeaning circumstances.658 These circumstances require a societal and interpersonal response in which those who are made susceptible are aided in a return to a positionality in which they are no longer suffering from factors that do not afflict others.

Kottow also recognizes illness as a form of susceptibility, given that those who are ill are both already suffering and become more susceptible to additional vulnerabilities due to their
illness.  This susceptibility of illness presents itself in a very specific manner when it comes to pregnant individuals with SUDs. For a large percentage of pregnant individuals with SUD, they were made susceptible to developing an SUD through their experiences of ACEs. Because the illness that they developed is one that is stigmatized and still not adequately understood both societally and by many healthcare professionals, their illness itself has made them susceptible to judgment, denial of access to care for their illness, and the threat of incarceration and/or separation from their child. While vulnerability and susceptibility are typically principles that inspire a duty of protection, in the case of pregnant individuals with SUD, this duty to protection is often denied due to discrimination and a lack of understanding of their illness, which only leads to an amplification of their susceptibility to greater harm.

b. The Effect of Substance Use Disorder on Maternal Subjectivity

While the type of legal and social harms to which pregnant and postpartum individuals with SUD are made susceptible will be explored more in section III, we will conclude section II by considering the effect that being made susceptible due to the ways in which SUD is misunderstood has on maternal subjectivity.

As Natasha White notes, traditional conceptions of Motherhood connote being a mother as a totalizing, stagnant identity that is wholly defined by the fact of having a child. Mothers are seen as self-sacrificing, constant pillars of stability through which their children can grow to understand their own dynamic selves, but who is not recognized as a self outside of her identity as a Mother once she has been given that role. Stories of mothers have often been told through the perspective of the child, the spouse, or through conversations about the extent to which pregnancy and motherhood preclude women from participating in social and work environments
to their previous full capacity. This has resulted in a social context which “situates women in a
ghostly state, in which the actuality of their being is denied. They are between the states of what
is perceived and what is experienced; they haunt the peripheries of our social vision.” In
contrast and opposition to these objectifying conceptions of motherhood in which children define
themselves as subjects in opposition to the maternal body, feminist psychoanalytic scholars have
posited various conceptions of maternal subjectivity, or, the ways in which women who have
become mothers assert their subjectivity and create identities for themselves that both
incorporate their self as a mother while also acknowledging that they have skills, dreams, and
identities beyond being a mother as well. Maternal subjectivity allows a new subjectivity to
emerge in which one is both a mother but also has the ability to create meaning and act as a
subject in the world.

In the context of individuals with SUD, discussions of maternal subjectivity become even
more complex. In contrast to the ideal of motherhood as a self-sacrificing, stable figure,
individuals with SUD are often stereotyped as selfish, unreliable individuals whose actions
cannot be trusted, particularly if those actions involve caring for child. While discussions of
maternal subjectivity typically entail defining oneself as an autonomous subject beyond
motherhood, individuals with SUD are already seen as autonomous figures who choose to
engage in activities that harm their children, not as individuals suffering from a chronic, severe
health condition. Well-resourced White women have fought for a maternal subjectivity that
endows them with personhood beyond the identity of Mother. However women of color, low
income women, women with SUD and other women who occupy identities that society deems
makes them a “bad mother” are on one hand presupposed more power and subjectivity in
decision making than they actually have while on the other hand are denied a core element of
their identity through the supposition that they have not “earned” their motherhood. This occurs, for example, through the determination in obstetric racism that poor newborn health outcomes are solely the result of maternal behaviors, or through the misunderstanding that the use of substances during pregnancy from a women with an untreated SUD is a “choice” over which she has complete autonomy and not a symptom that has not been probably managed with the help of healthcare professionals).

While traditional discourse around maternal subjectivity describes the challenges of mothers to be seen in their full personhood due to their being mothers, for mothers who are seen as deviant, the challenge becomes being seen as a mother at all. This depiction of the “bad mother who uses drugs” has had immense impacts on how pregnant and postpartum individuals are viewed legally and socially, and the view that mothers with SUD are an inherent threat to their children has persisted, even as attempts have been made to alter the ways in which we respond to substance use disorders as a society.

III. Whose Safety Matters?

Safety has been a central component of conversations surrounding maternal substance use. However, discussions of safety within this context have primarily focused on infant safety and the concerns for safety raised within these discussions have not been grounded in evidence or established best practices.
a. Exploring the History of the Weaponization of Infant Safety in the Response to Maternal Substance Use

As we have touched on earlier in this chapter, the term “mother blame” is used to describe the phenomenon in which pregnant individuals are held “exclusively responsible for the ill health of their children.”666 This understanding of maternal and fetal/newborn health is deeply flawed, both because it does not have a grounding in scientific evidence and actively discounts the ways in which individual’s environments, social, and economic world impact their health status, but also because the way in which this understanding was developed and operates is often deeply rooted in bias and discrimination.667 Mother blame in the context of maternal substance use is widespread and difficult to dismantle as a dominant narrative because even as scientific research has illustrated that substance use disorders are chronic, persistent medical conditions that are not a result of poor morals, the wider cultural bias against individuals with substance use disorders—especially those who happen to get pregnant—has persisted.668

In the context of pregnancy and substance use, our systems have not yet shifted to support the updated information about the nature of substance use disorders and their impact on pregnant individuals and their children. As it currently stands, many states have mandatory reporting laws that require healthcare workers to report when babies are born with symptoms of substance exposure (or even worse, when babies or mothers have a positive drug toxicology screen on labor and delivery, often administered without patient consent) that place these families in contact with child welfare and legal systems whose level of surveillance and response to their needs has been shown consistently to vary widely depending on the race, socioeconomic and national status of the families in question.669
Through her experience studying the history of the criminalization of pregnancy in the United States, Michele Goodwin has noted that, “a key link in the numerous arrests and prosecution of pregnant women throughout the United States is their medical providers, whose roles as undercover informants…believe their sacred fiduciary obligations. From their once revered role of fiduciaries, duty-bound with protecting and promoting the interests of their female patients, some medical providers now police their pregnant patients’ conduct and even serve as quasi law enforcers for the state.” This dynamic can be seen in a case already cited in which a pregnant woman was arrested and charged after accidentally falling down the stairs and miscarrying because her nurse suspected that she had intentionally thrown herself down to incite a miscarriage, and in cases such as that of Rennie Gibbs in 2006. Rennie Gibbs was prosecuted in Mississippi for “depraved heart murder” after experiencing a stillbirth. Rennie Gibbs was an African American teen with a substance use disorder that went untreated during her pregnancy. When she experienced a stillbirth, she was then arrested and charged after a medical examiner claimed that her continued substance use during pregnancy, “demonstrated indifference toward the life of her fetus and that its death was the direct result of her depraved heart.”

Rennie Gibbs was only fifteen years old at the time of her pregnancy, and the motive to declare the stillbirth a murder on the part of the medical examiner was certainly motivated not only by a misunderstanding of substance use disorders, but also of the substance which Ms. Gibbs was using: crystallized cocaine. Research has since demonstrate that pregnancy demise is not associated with the use of crystalized cocaine, but the racially-motivated social messaging of the 1980s and 1990s around this substance through the “war on drugs” led to deeply entrenched beliefs about its impact even among healthcare professionals, despite the fact that those beliefs
are not grounded in scientific evidence. Because of the still deeply-linked connection between substance use disorders and the law, healthcare providers are often acting as interpreters of the law instead of medical professionals, with the rationale that they are protecting the safety of unborn or newly born children.

Healthcare workers have taken on the role of assessing the criminality of their patients; something about which they have no training and which actively harms their ability to provide medical care to patients they deem as “at risk” of harming their unborn or born children (even if the identified reason for “risk” has no proven causal relationship to child abuse). In the case of SUDs, a chronic, persistent illness has been criminalized instead of adequately treated and patients suffering illness are blamed for their untreated condition and considered a perpetrators of child abuse in the minds of many healthcare workers.

In theory, mechanisms for identifying and responding to maternal substance use disorder have claimed to defend the safety of children. In practice, they have harmed children and parents alike, and have served more as a mechanism of punishment for women without providing the resources to receive needed medical treatment.

b. The Ethical Significance of Centering the Mother-Infant Dyad in Our Response to Maternal Substance Use

The weaponization of infant safety and the neglect of responsiveness to the needs of mothers with substance use in pregnancy has had dire consequences that persist and create barriers to entry and retention into SUD treatment for mothers. In a study focused on understanding the experiences of mothers with Opioid Use Disorder (OUD), a research team found that four themes cut across women’s experiences as barriers to recovery: 1) women
experienced feeling a lack of autonomy in taking medications for OUD when pregnant; 2) women were concerned about taking their medication for OUD because of “perceived harms to their newborn,” who might be born with a withdrawal syndrome or symptoms of withdrawal due to their taking their medication; 3) there was fear of loss of custody due to mandatory reporting requirements and of judgment from their healthcare teams; 4) many treatment providers, such as methadone clinics, did not provide gender-responsive care.

In regards to the first theme, women felt pressured and at time coerced into either taking medication for OUD despite not wanting to, or in other cases, to taper medication when they did not know if they were ready; one patient even reported being pressured to terminate her pregnancy due to her being on medications for OUD, as prescribed by her treatment provider. In regards to the second theme, patients reported that there was increased scrutiny from healthcare providers about their behavior immediately postpartum, judgment from healthcare team members if their baby experienced withdrawal symptoms. In regards to the third theme, the involvement of Child and Family Services was a distressing component of pregnancy and the postpartum period; for mothers with past involvement in the system, it was a source of fear, and for many first-time mothers, the fact that Child and Family Services would be involved at all had not been disclosed to them until after their baby was born. Even if a woman is prescribed Subutex for OUD and takes her medication as prescribed, she is still reported on to Child and Family Services. In the words of one of the study participants: “Even if you do everything right at the end of it, there’s still going to be system involvement.”

Despite Medication for OUD being established as a best practice clinically, rates of prenatal and postpartum utilization and retention have not been high. In follow-up discussions, women identified having more trust built with providers before entering into
conversations about medication use, the need for a more personalized, attentive approach to their treatment, and using a shared decision-making model to determine course of treatment for their OUD as potential ways to improve their care and promote engagement in treatment. The women also clearly identified that healthcare providers need to be upfront and transparent about any mandatory reporting requirements and the involvement of Child and Family Services. However, the study also notes that, “until MOUD exposure is decoupled from mandated reporting, even comprehensive counseling may be insufficient, because the perceived threat is great. Individuals with OUD should be able to make treatment decisions based on medical risks and benefits, in the same way that other therapies such as antidepressants are recommended, without the fear of child protective services reporting and investigation.”

This study highlights the need for more responsiveness to the unique needs of pregnant and postpartum individuals with substance use disorders, including OUD. Because the response to OUD has been to criminalize and punish pregnant individuals, even those who enter treatment and take their medication as prescribed, entrance and maintenance in treatment continues to be a perilous decision for women who do not want to lose custody of their child. They fear the judgment of healthcare providers, and feel as though they do not have a say in their own course of treatment. ACOG itself has noted that punitive responses to perinatal SUD have been shown to increase avoidance of care and have led to poor health outcomes for the dyad. Despite this, responses to SUD in many states have only grown more punitive in recent years.

We are making babies sicker by failing to adequately care for their mothers. Pediatrician Matt Grossman, the co-creator of the Eat Sleep Console approach for treating babies with opioid withdrawal syndromes, has notably said that when it comes to caring for babies with withdrawal syndromes, “Mom is medicine.” One of the most effective treatments for babies born with
opioid withdrawal symptoms whose mothers are on medication for OUD is breastfeeding (because the traces of MOUD in breastmilk help them wean and reduce withdrawal symptoms) and being held by their mother.\textsuperscript{685} Pregnant and postpartum individuals deserve to be cared for treated with respect and dignity because of their humanity and personhood. Their right to healthcare is not dependent upon their status as a parent. But in the case of the mother-baby dyad effected by maternal substance use, denying mothers care that is not responsive or adequate to address their needs or enhance their dignity also results in a reduction of the quality of care for the infant because it denies the baby its best medicine: a healthy mother. Without becoming more responsive to both needs of the dyad, including the maternal needs, we will continue to fail both sides of the dyad.

IV. Plans of Safe Care: A Pathway to Responsive Care

As a part of the requirements for receiving Child Abuse Prevention and Treatment Act (CAPTA) and the later Comprehensive Addiction and Recovery Act of 2016 (CARA) funds, states must provide a variety of programming, including Plans of Safe Care.\textsuperscript{686} The following section reviews the Plans of Safe Care structure and its potential for use beyond the population of infants with prenatal substance exposure and their families.

a. Plans of Safe Care: An Introduction

A Plan of Safe Care (POSC) is defined federally as, “a plan designed to ensure the safety and well-being of an infant with prenatal substance exposure following his or her release from the care of a healthcare provider by addressing the health and substance use treatment needs of the infant and affected family or caregiver.”\textsuperscript{687} The team involved in POSC creation and
implementation is typically the healthcare providers of mom and baby, child welfare, community-based organizations focused on early childhood development, and substance use treatment centers. While the federal government requires that the plan be in place and that the plan includes resources to address the substance use disorder needs of parents or caregivers, the specifics of how these plans should be structured and what requirements are entailed beyond the mere existence of a plan varies by state. Moreover, State child welfare departments have largely chosen to transfer the responsibility of determining POSC requirements and workflows to individual counties. As we will see in the following section, this has had major impacts on the current state of POSCs.

However, for the purposes of this introduction to POSC, we will first focus on elements of the POSC that are beneficial to the care of the dyad. POSC require collaboration across both medical and social services and create a shared account of the overall health needs of the child and the mother, including considerations for the treatment needs and progress of maternal substance use disorder. POSC should also be co-created with families, and are a living document meant to facilitate and enable better communication amongst families and the various healthcare professionals and social service agencies with which they may be involved, including SNAP, WIC, etc. Families have the option to accept or deny participating in a POSC, but they are encouraged to accept the plan, as it is often a way to illustrate that they are making progress in their recovery to Child & Family Services.

In theory, POSC are a multidisciplinary, coordinated attempt to care for families with special needs in a wrap-around manner. This is an admirable goal, and a goal that is worth striving towards and which I wholeheartedly support. However, in practice, POSC have failed families in many ways. The first, and one of the most significant manners in which POSC is
antithetical to the goal of supporting families, is that it requires and is often prompted by, a mandatory notification to Child and Family Services of maternal substance use. Federally, the only requirement is that the overall number of substance exposed newborns are reported in aggregate to determine need and funding. However, many states have specified that upon confirmation that a baby was born with in utero substance exposure, a mandatory report must be made. In some states, there is a stated difference between this type of notification and a report of child abuse; for example, in the state of Pennsylvania. However, even in states where there is a stated difference between notifications and reports, state agencies have not clarified what this distinction entails in practice. In some states, such as the state of North Carolina, there is no stated difference; all cases of identified prenatal substance exposed newborns follow the same procedure with child and family services when a notification is made as they would if a report of child abuse or neglect is made. This is significant and detrimental to the overall goal of POSC, for reasons that will be further explored in the next section.

As it currently stands, at best, Plans of Safe Care are disjointed, inadequate, county-specific attempts to provide needed services to families effected by substance use. At worst, Plans of Safe Care act as a mechanism to further strengthen the relationship between healthcare providers and the criminal justice system, turning healthcare workers into agents of the state. Substance Use Disorders are serious, chronic illnesses that should prompt a robust, multi-disciplinary social and medical response and the POSC framework is a framework with an immense amount of potential due to its multidisciplinary nature, co-creation with parents, and emphasis on coordinating care across the continuum and across behavioral and physical health. However, in a context in which child and family services are inextricably tied to legal systems,
the creation and implementation of Plans of Safe Care that require mandatory reporting and child welfare involvement it is not a politically or morally neutral decision.

**b. Beyond Substance Use: The Necessity of Expanding a Plans of Safe Care Approach**

With the understanding that the POSC approach needs to be uncoupled from its legal and child welfare ties, the basic structure of the POSC model is a framework whose scope, if expanded, could greatly benefit patient populations beyond those experiencing substance exposure. To illustrate this, we will consider the case of individuals with mental health conditions (e.g. anxiety, postpartum depression, etc.). Mental health conditions have been identified as one of the leading causes of pregnancy-related deaths in the postpartum period.\textsuperscript{694} In fact, perinatal depression has been identified as the leading complication during pregnancy and the postpartum period, with 1 in 7 women identifying as having been affected by depression.\textsuperscript{695} Instances of these conditions can be more prevalent and can worsen after childbirth for women of color due to stress from experiencing racism and instances of mistreatment from medical providers during the experience of given birth.\textsuperscript{696}

As with SUDs, postpartum mood disorders often require additional medical support through the receipt of behavioral health services such as psychiatry and Cognitive Behavioral Therapy. They may also be exacerbated due to financial and social stressors, and might require new families to have additional social supports in place in order to ensure that both members of the dyad are care for and thriving. If an individual is experiencing severe symptoms of depression, it might be difficult for her to do daily tasks, and in some cases of postpartum depression, it is difficult for mothers to spend time with their children, resulting in the need for additional supports in place. Moreover, the potential need for psychiatric medications and
medication monitoring and changes over time can add additional medical considerations to the care of mothers during this period of time. If we consider the structure of the POSC in this context, it is clear that there are elements that would support the health of new families in the context of perinatal mood disorders as well. The POSC is a co-created, voluntary document in which parents, healthcare providers, social workers, and additional social supports (including community-based organizations) can collaborate in a shared space about the supports a family needs and the specific steps all parties are taking to ensure that mom and baby are care for well. One of the biggest barriers to continuity of care for patients with behavioral health conditions is that concerns about the maintaining the confidentiality of behavioral health conditions patients might be experiencing has resulted in strict protocols about information sharing specific to behavioral health concerns. Moreover, even in cases in which the law might allow for information about a patient’s mental health to be shared for continuity of care purposes, mental health providers might have personal concerns about sharing this information that prevent them from disclosing their patient’s health information. The POSC structure supports information sharing between providers but does so in a very structured manner that supports the confidentiality and autonomy of the patient. As the driver of the POSC, the family decides what type of information needs to be shared, in what context, and for how long. And because the POSC is voluntary in nature, if a patient is uncomfortable with their providers engaging at all, they have the ability to state that they would not like to participate in the POSC.

In an ideal world, all families would be offered a POSC in which they would have access to a social worker who could connect with them to have a structured conversation about any needs they may have as they adjust to life with a new child and who can connect them to
community-based organizations and resources that they could access if new needs arise. While staffing and capacity limitations may not allow for this, at minimum, if we are able to divorce the POSC structure from any kind of mandatory reporting mechanism, this structure could serve as a supportive framework for families that are impacted by behavioral health conditions in the postpartum period.

V. Limitations of Plans of Safe Care

Co-created, wrap around services for families that need support across social and medical arenas is absolutely necessary and should be supported. However, in order for these plans to be truly supportive and promoting of the health and wellbeing of families, they need to be completely divorced from any mandatory notifications to governmental agencies. Substance use disorders, mental health conditions, social needs, and other criteria that might be addressed in a plan of safe care are all public health concerns, not criminal or legal concerns. Unless if there are clearly defined and clinically-indicated reasons to suspect actual abuse or neglect of a baby in the postpartum period, child and family services should not be involved in lives of new parents and their children.

a. The Need for Guidance in the Conceptualization and Implementation of Plans of Safe Care

As we saw in Section IVa, the federal guidance around POSC has been limited. The guidelines for POSC requirements were not accompanied by structured plans for implementation on either the state or county level, which has resulted in large variability in policies and a lack of adherence at the state level to even the minimal guidance that was given federally.699 A 2020
study housed at the University of Connecticut found that only two states are fully compliant with the CAPTA/CARA legislation, and 71% of states are only compliant with one or zero out of 5 stated domains in the CAPTA/CARA legislation. Part of this variability and lack of compliance with the federal requirements could be due to a vast increase in funding at the state level that has not been distributed to frontline hospital workers (who are the ones tasked with understanding and implementing notification requirements, as well as participate in the creation of the POSC), and the lack of technical assistance provided at the state, county, and hospital level.

Because there has been a lack of guidance about how the POSC should be interpreted, coordinated, and implemented, there is concern that the lack of clarity on the purpose and structure of POSC is leading to an increase in negative and inequitable outcomes, such as greater surveillance for mothers on prescribed Medications for Opioid Use Disorder due to withdrawal symptoms their babies might experience, greater child welfare involvement for families of color, and an increase of likelihood that the child will be removed from the home. As a result of these findings, the University of Connecticut study researchers proposed the following potential improvements: more robust and continued technical assistance and training about POSC, as well as more robust stakeholder engagement, additional training for hospital social workers on best practices for treating substance-exposed newborns, POSC policies that differ from traditional child welfare safety planning, more research about the potential “net-widening effects” of states’ interpretation of CAPTA/CARA, and the overall need for support and oversight over the implementation of POSC.

This potential “widening effect” in particular is of great concern in this context. Lloyd et al state that, “the phenomenon of net widening is a potential unintended consequence of
diversionary programs that aim to leverage historically, or functionally punitive social systems to provide services. Net widening results when professionals in these systems (e.g. law enforcement, child welfare workers) consider the diversionary program and, within the intention of providing ‘high risk’ people access to the program, increase arrests or case initiation. These actions, then, put more people in contact with the system, or keep them in contact longer, than before the diversionary program existed.”704 Because states have interpreted and expanded the scope of certain aspects of POSC inclusion, there is a risk of net-widening, with serious concerns of this net-widening leading to an even larger increase in child welfare involvement, which as we will explore in the next subsection, historically and contemporarily is marked by severe racial and ethnic inequities in referral and responses.705

The lack of clear guidance and failure to standardize understandings of CAPTA/CARA legislation across states and across counties has led to huge variability on all fronts. Anecdotally, as someone who has had conversations with hospital teams and county child welfare agencies from multiple counties across multiple states, I have found that the response to substance-exposed newborns and how collaboration to connect their families to resources is handled varies drastically depending upon the county in which a baby is born and the general attitudes the nursing staff and social workers at individual hospitals have towards maternal substance use. When there are not clear guidelines on what is required and how to meet those requirements, the space for bias and discrimination to act as a determining force in how families are treated widens.
b. Addressing the Historical and Contemporary Racist Practices of Child Protective State Agencies as a Barrier to Effective Plans of Safe Care

While the justification for the mandatory reporting of maternal substance use is fear of child abuse, there is no indication that maternal substance use causes child abuse or neglect. Moreover, when considering the higher correlation of rates of child abuse and neglect when parental substance use is present, it is crucial to note that these rates reflect situations in which parent(s) have often not sought or received treatment due to fears of incarceration, the removal of children from their home, etc. When behavior that is symptomatic of a health condition is criminalized and punished and the disease therefore goes untreated, individuals often find themselves in situations in which other high-risk behavior take place. Research has illustrated that when offered treatment, pregnant individuals are more likely to want to engage in treatment for substance use disorders, most likely because they want to get better for their child. Pregnancy is often a catalyst to initiate recovery, but if the cost of accessing treatment is mandatory involvement with the legal system, many individuals will continue to hide their illness to the best of their ability out of fear and justified distrust of unjust legal and social institutions.

To understand why individuals fear the involvement of child welfare and Child and Family Services to the extent that they do, we must consider the racist practices of child welfare and child and family services agencies in the United States. Dorothy Roberts and Michele Goodwin have created social and legal genealogies of the racism of child welfare systems in this country. For the purposes of this subsection we will not be able to explore these genealogies in depth; I highly recommend reading both Shattered Bonds: The Color of Child Welfare and Policing the Womb: Invisible Women and the Criminalization of Motherhood. Despite the fact
that studies have shown that the incidence of child maltreatment among Black families is not
greater than other racial groups, Black families are disproportionately represented in the child
welfare system.\textsuperscript{710} The federal government itself has noted that, “findings suggest that different
race/ethnicities receive different attention somewhere during the process of referral,
investigation, and service allocation, and that the differential representation of minorities in the
child welfare population does not derive from inherent difference in the rates at which they are
abused or neglected.”\textsuperscript{711} Black families are more likely to be reported to child welfare authorities
than other racial groups, and their treatment once reported differs greatly as well.

This has been illustrated most clearly (and is most relevant to the discussion we have
been having in this chapter thus far) in the ways in which substance use has been treated in Black
families. Roberts notes that Black women are “far more likely to be reported for prenatal
substance abuse to have their newborns placed in out-of-home care.”\textsuperscript{712} While substance use
between White and Black women has been found to occur at approximately the same prevalence,
Black women are ten times more likely to be reported than White women and 72\% more likely
to have their child removed from the home by child protective services once involved in the
system.\textsuperscript{713} The US DHHS report cited earlier also confirms that, “even when families have the
same characteristics and lack of problems, African-American children, and Hispanic children to
a lesser extent, are more likely than white children to be placed in foster care.”\textsuperscript{714} Roberts notes
that, “vague definitions of neglect, unbridled discretion, and lack of training form a dangerous
combination in the hands of caseworkers charged with deciding the fate of families.”\textsuperscript{715} In the
years since Roberts’ seminal book was published, this overrepresentation of Black families in the
system and the prevalence of family separation that occurs has not gotten better. In 2018, “Black
children represented 14\% of the total child population but 23\% of all children in foster care.”\textsuperscript{716}
Moreover, the timeline which Child and Family Services often gives mothers to achieve and maintain abstinence from substances or lose parental rights to their child(ren) is unrealistic in the context of the disease progression of the illness they are experiencing.\textsuperscript{717} Parents are often given 6 months to successfully complete a treatment program for their substance use disorder. However, the time it typically takes to achieve recovery is often a much longer period, which means that the child welfare process for reunification flies directly in the face of what research has shown to be true for the disease process of substance use disorders.\textsuperscript{718}

\textbf{Conclusion}

In a context in which racial inequities in child welfare involvement and racial disparities in family unification and family health outcomes persist, the proposal to streamline processes to funnel families from hospital care into the child welfare system should be viewed critically. To this point, despite the efforts that have gone into creating and streamlining POSC processes, child and family services organizations and the child welfare system itself have not been clear or transparent about any changes they are making to try to ensure a less discriminatory approach to their work. Until there is either the complete fissure of POSC from the child welfare system or a clearly illustrated, intentional transformation of the child welfare system itself, the threat of the promotion of POSC causing a net-widening effect will persist and our systems of response to prenatal substance use will continue to act as a deterrent to individuals with SUD receiving the care and treatment they desperately need.
6b. It Takes a Village: The Role of Diverse, Multi-Disciplinary Team-based Approaches to Care in Improving Maternal Outcomes

Introduction

This section will examine the current state of the maternal health workforce in the United States within its historical context in order to understand the role of racism in shaping the lack of racial and ethnic diversity in the contemporary American maternal health workforce. A disproportionately high number of maternal health staff, including OB/GYNs, midwives, labor and delivery nurses, and doulas, are White. This lack of racial/ethnic diversity among maternal health staff constitutes a major barrier for reducing disparities in Black maternal health outcomes. Moreover, the lack of diversity in the maternal workforce is the direct result of discriminatory practices enacted in the 20th century, during which White obstetricians targeted midwives of color and sought to push them out of practice. Until this history has been understood and reckoned with, strides towards cultivating more diverse, inclusive workforces will not be made to their full potential.

I. The Unbearable Whiteness of the Maternal Health Workforce

The American College of Nurse Midwives (ACONM) and the America College of Obstetricians & Gynecologists (ACOG) have both noted that there is a marked lack of diversity in the midwife and OB-GYN workforce.
a. Examining the Current State of the Maternal Health Workforce in the United States

Research has shown that racial and ethnic diversity in healthcare professionals promotes increased access to healthcare services and better health outcomes for underserved populations. While a lack of diversity in the maternal healthcare workforce is not the sole reason for continuing, worsening health inequities, it is significant that patients are often unable to receive racially and/or culturally concordant care when the desire for that care is expressed. Nursing as a profession overall has struggled to work towards more diversity in the workforce; from financial and cultural barriers to education, limited economic opportunities that are the result of inequitable social policies, and educational environments in nursing schools that are often unwelcoming and un-diverse, there are barriers to entering and remaining in both nursing education and nursing as a field for individuals of color. Since the publication of the Institute of Medicine’s report, “Unequal Treatment; confronting racial and ethnic disparities in health care” twenty years ago, there have been widescale projects to increase the diversity of healthcare workforce, and in particular, the nursing workforce, but despite these efforts, the nursing workforce remains lacking in diverse representation.

Of the approximately four million people who give birth every year in the United States, 47% of these people on average are racial and ethnic minorities. A recent national survey of certified nurse midwives revealed that more than 90% of certified nurse midwives identify as non-Hispanic White. There is not currently data available on the racial and ethnic composition of the maternity nursing workforce as a whole, but it has been noted that, “the demographics of the maternity nursing workforce reflect racialized access to the profession, making it difficult to combat racial inequities in maternal health outcomes.” Structural barriers persist that make it more difficult for people of color to enter and successfully complete nursing programs and to
successfully find supportive post-graduation placements. The lack of equitable access to the nursing profession that results perpetuates healthcare systems in which inequitable care is provided. Given the findings of the Giving Voices to Mothers study that we have already discussed previously in this dissertation, the vast inequities in maternal mortality and severe maternal morbidity, and the prevalence of reported discrimination during hospitalization for child birth, it is clear that the underrepresentation of communities of color in the maternal health workforce must not persist.728

b. Understanding the Role of Racism in Shaping the Lack of Racial and Ethnic Diversity in the Contemporary American Maternal Health Workforce

While lack of diversity in the healthcare workforce is a continuing issue, there are specific dynamics in the maternal health workforce’s lack of diversity that have their root in the manner in which obstetrics as a field came to prevalence and the treatment of Granny midwives.729 The field of obstetrics as we know it in the United States has its origins in the antebellum South, where doctors would test new medical procedures on Black enslaved individuals, whom they had access to through their role as appraisers to assess the monetary value of women, and Irish indentured servants, who were used to explore doctors’ experiments into the “differences” between White and Black female bodies.730 Because enslaved individuals were often in need of medical care due to the inhumane conditions in which they were forced, doctors were able to make new discoveries and pioneer new medicine procedures through their experimentation on these women. This process was fueled both by the ban of importing of slaves from Africa in 1808 and the subsequent desire from Southern plantation owners to increase the birth of enslaved individuals, and by the prestige that doctors gained by having access to the
seemingly endless number of bodies on which to experiment. By the time Gynecology was established as a formal field in the 1870s, there had already been ample research on Black enslaved women and their Irish counterparts to garner doctors financial success and professional respect in the medicine field. Doctors would take the techniques and procedures they had fine-tuned on enslaved and, after the end of the Civil War, poor women who had no other options, and would use them to treat and cure gynecological conditions in well-resourced White women.

This new, White male-dominated field differed from traditional methods of childbirth and care during pregnancy in many ways, but one of the most notable ways as it pertains to the lasting effects on the maternal health workforce is that it shifted the experience of childbirth from one in which a woman was supported by another woman—typically a midwife, or an older female relative who could help support the childbirth process—to a more sterilized, medicalized process in which men were the locus of knowledge and deliverer of children. As gynecology was still coming into being, the experienced community leaders in Black communities, often referred to as “Granny Midwives”- still continued to attend deliveries for enslaved individuals and were often tasked with attending the births of White plantation-owning women as well. After the conclusion of the Civil War and the abolition of slavery, Granny Midwives continued to attend deliveries for women of all races in the rural South, due to the inaccessibility of hospitals for most people in rural areas, and the reluctance of doctors to see poorer patients or travel to remote areas. For a time, gynecologists delivered babies in hospitals and midwives attended births in rural and low-income settings, and there was little overlap in the populations they served.
However, in the twentieth century, there was a drastic shift from the majority of births occurring at home to the 64% of births occurring in hospitals by the year 1940.\textsuperscript{736} The rise of maternal deaths between 1900 and 1940 caused the government to implement state health regulations for physicians and midwives. While historians of obstetrics suggest that this shift and the co-occurring rise in maternal deaths were most likely the result of the failings of general medical practitioners who lacked knowledge of obstetrics and lack of basic hygiene, there was a concerted effort on the part of obstetricians and gynecologists to blame midwives for these poor health outcomes, despite no evidence to suggest that this was the cause.\textsuperscript{737} While some midwives were able to accommodate the new regulations, many of the midwives who had learned their trade through apprenticeship, found it difficult to adapt. The number of midwives during this time decreased drastically, with the number of Black midwives in particular decreasing due to the often explicitly racist claims of obstetricians that they were unknowledgeable and harmful to their communities.\textsuperscript{738}

Through the formation of obstetrics and gynecology as medical fields, childbirth went from being perceived as a natural part of the lifespan that was supported by women (midwives and family members) to a health condition that required medical intervention through an obstetrician.\textsuperscript{739} This shift in perception was achieved through the discovery of “medical breakthroughs” by experimenting on enslaved individuals and through the discrediting of the knowledge and practices of Black Granny Midwives in order to justify the need for an obstetrician at all births. This history has left its mark on both the current power dynamics between OB-GYNs and midwives, and the lack of diversity in the maternal healthcare workforce, even midwifery.
II. The Ethical Significance of Promoting Diversity in the Maternal Health Workforce

This section will explore how increasing diversity in the maternal healthcare workforce can promote the safety of mothers and infants, decrease racial inequities in maternal health outcomes, and further the goal of providing dignity-enhancing care.

a. The Role of a Diverse Workforce in Promoting Responsive, Good Care

Research supports an increase in Black providers as a key strategy to improve access to care and quality of care for Black patients. In inpatient hospital settings, recent research has suggested that gender or race matching of doctors and patients can reduce mortality rates. In a study exploring the impacts of racially concordant preventive care, investigators found that Black patients in the study were more likely to receive a preventative care screening when the screening was offered by a Black doctor, and that patients who expressed distrust of healthcare systems were more open to getting preventative tests done after seeing a Black doctor. There are many reasons why this might be the case. Studies have suggested that racially concordant care results in better communication between healthcare provider and patients. And given the well-earned distrust many minority patients may have of the medical system due to historical injustices such as the Tuskegee experiment, having a racially concordant provider may help alleviate concerns that providers do not have patient interests at heart. Joy Cooper has noted that, “having a provider that does not require you to code-switch, or shift your language, is edifying and comforting. Racially-concordant care focuses on making individual patients feel seen and affirmed in their presence.”

It is extremely important to note that a call for more diversity in the healthcare workforce and a recognition of the importance of having racially-concordant care as an option for patients
is not being posited as the *only* solution to improving health inequities or as a way to shift responsibility from White healthcare workers from having to address and confront internalized racism and bias. Rather, recognizing that having racially-concordant care as an option for patients underscores that one of the ways in which patients may feel seen and heard in healthcare settings is through seeing healthcare professionals who share their race, ethnic or cultural identities. Particularly in a context in which healthcare as a whole has failed for decades to decrease inequities in health outcomes across most health conditions, having racially concordant options for patients is a necessary step towards ensuring more responsive, patient-centered care. Moreover, to return to Jones’ levels of racism, a lack of representation in a healthcare setting signals to patients that elements of institutional racism are present at the organization through which they are receiving care, which could increase concerns that they might receive personally mediated racism when attending medical appointments. Jones defines personally mediated racism as, “prejudice and discrimination, where prejudice means differential assumptions about the abilities, motives, and intentions of others according to their race, and discrimination means differential actions toward others according to their race.” Personally mediated racism is the level of racism most obviously seen within interpersonal relationships, and is the level of racism that is frequently targeted in implicit bias trainings and other educational efforts to help healthcare staff understand the underlying beliefs and prejudices they might have and carry into their professional and personal relationships. Moreover, as Yolonda Wilson has argued in the Hasting Center’s 2022 “A Critical Moment in Bioethics: Reckoning with Anti-Black Racism Through Intergenerational Dialogue,” prioritizing *only* individual trusting relationships in understanding the lower rates of Black patients accessing healthcare services glosses over the continued structural elements that contribute to justifiable distrust of
healthcare systems that patients might have. Personally-mediated racism is perpetuated through inequitable healthcare systems; in order to create equitable healthcare cultures, efforts must target the interpersonal and structural elements that lead to both inequitable access to healthcare professions and inequitable access to quality healthcare services.

b. Diversifying the Maternal Health Workforce in the Movement Towards Health Equity

Given the prevalence of mother blame narratives and obstetric racism that we have discussed in previous chapters of this dissertation, having racially concordant options for care in the context of pregnancy and childbirth is exceptionally important, as it can provide one less barrier to receiving understanding and respectful attitudes from healthcare providers in a context in which an individual may feel overly-surveilled and distrusted as a caretaker for their child and their self. While racially-concordant care is not a guarantee that there will not be experiences of discrimination or other preventable negative outcomes, it does decrease the likelihood that maternal patients will be met with the assumption that they mean to do harm to their child.

Moreover, a substantial increase in diversity in the maternal health workforce would necessarily entail and require the restructuring of discriminatory elements that have excluded and discouraged people of color from entering and remaining in these spaces. Elements of successful programs that have recruited and retained more diverse graduate and professional students have identified that the following elements are shared among these programs: 1) they are “comprehensive programs that employ a combination of interventions such as financial supports, social supports, mentoring, and intensive training opportunities”; 2) they have targeted recruitment and restructured admissions policies in a way that prioritizes more holistic assessments of candidates over traditional application processes; 3) they provide addition
opportunities to promote interest in programs (e.g. through summer enrichment programs); and
4) they have innovative and enhanced program curriculums that center the importance of
reducing health inequities.751

By restructuring the organizational and cultural environment of a healthcare organization
in ways that would recruit and retain more diversity in the workforce, the overall environment
would inherently become one in which individuals from more diverse backgrounds would be
more supported and receive more responsive, respectful care. To draw a parallel from Martha
Nussbaum’s analysis of the routine shame that individuals with disabilities are often subjected to
in navigating society, the problem is that we have built our healthcare settings to be
environments which cater specifically to the needs and desires of White patients and White
healthcare workers, who often do not have the same experiences or concerns of people of color.
The needs of individuals of color in these spaces are not “abnormal” or unreasonable; we have
simply failed to create environments that are actively receptive to the needs of non-socially
dominant groups. In Nussbaum’s words: “Our society caters for the one, and…has neglected the
other.”752 The ways in which our current environments are structured and organized is meant to
welcome and support socially-dominant groups. If we restructure our environments to be ones in
which socially-disempowered groups are actively supported and are able to flourish, those
environments support the care and flourishing of patients from socially-disempowered groups as
well.
III. A More Diverse Workforce is Not Enough: The Need for Multi-Disciplinary Care Teams in Maternal Health

Having now examined the role that increasing racial/ethnic diversity can play in providing better, more just maternal care, Section III will consider the role that increasing the use of multi-disciplinary teams can play in providing better, more just maternal care.

a. Understanding the History of Obstetric Violence and Gatekeeping in the United States

Despite having more prenatal care than any other country, maternal mortality rates in the United States are higher than in any other developed country and continue to rise. This indicates that quantity of care is often not at fault in pregnancy-related deaths, but rather, the quality and type of care available. This is, of course, not to say that lack of access to care is not an issue for specific patient populations, but rather that the overall negative health outcomes and rates of maternal mortality cannot be attributed to solely to a lack of access to care. As we touched upon previously, part of the way in which maternal health care services have been structured is a result of the way in which obstetrics and gynecology as a field was developed. This subsection will explore more specifically the ways in which the obstetric gatekeeping of the twentieth century contributed to the current landscape of prenatal care in the United States.

Granny midwives were given their specific name because they tended to be older women, trained through apprenticeship, and typically only took over as a full midwife after the midwife under which they apprenticed retired. They were integral, well-respected members of their communities—largely rural areas in the South Eastern region of the United States—until the late nineteenth to early twentieth century when medicine took on a tone of professionalism, self-identifying as, “a [special] body of knowledge, requiring extensive training [with its licensed
During this shift towards the professionalism of medicalized birth, women were encouraged to give birth in hospitals, where pain-relieving drugs could be administered to help with the birthing process. Health officials and medical doctors alike blamed granny midwives for the rise in maternal mortality rates, and depicted them as unqualified, unsafe, and unprofessional, which contributed to the rise in prestige of physicians and the decreasing number of women seeking care from granny midwives.

The rhetoric used to discourage the utilization of midwifery services was often explicitly sexist and racist in nature, citing the common belief that women are weaker and less intelligent than men and the equally common belief that African Americans are unintelligent and “primitive” in nature. These beliefs were also perpetuated by cartoons in circulars paid for by public health authorities that showed granny midwives as unclean, unintelligent, old and feeble. This public and cultural depiction of midwives as unclean unqualified practitioners eventually resulted in legislation that sought to “limit or eliminate midwifery in its entirety” which included, “restrictive medical licensing laws and more rigorous medical education,” both of which were largely inaccessible to midwives due to economic, social and gender-based discrimination and due to the fact that most of the granny midwives in particular lived and worked in rural areas.

Bonaparte argues that, “once white medical men asked society to acknowledge their authoritative knowledge (or exclusive right to birthing work) and obtained legal backing via licensure requirements, the US social structure and culture embraced the necessity and ‘expertise’ of white men in birthing rooms.” This is significant because the knowledge, expertise and authority of white male doctors was carved out in this space in direct opposition to
that of Black granny midwives and midwives in general. Using medical journals to smear the work of midwives, racist arguments to justify excluding Black individuals from practicing medicine in general, and sexist beliefs about the inherent inferiority of women, white male doctors propelled themselves into prominence and shaped the field of obstetrics. When considering the prominence of hospital births and the hold that—until recently—OB-GYNs have had over birthing individuals, it is important to note that this shift in where birth occurs and who is considered the authority in the labor and delivery room was not an accidental happenstance but the result of a targeted, ongoing attack on midwives, the Black community, and women.

b. Midwives, Doulas, and Perinatal Community Health Workers: Essential Components of Responsive Care Teams

Given the extent to which OB-GYNs berated the skill of midwives and mocked the presence of non-professional women in the birthing process, it is interesting to note that health outcomes for patients who receive care with midwives integrated into the care team are substantially better than those who deliver with an OB-GYN, and health outcomes when a doula is involved in the birthing process are also substantially improved. A midwife may be defined as a “responsible and accountable professional who works in partnership with women to give the necessary support, care and advice during pregnancy, labour and the postpartum period, to conduct births on the midwife’s own responsibility and to provide care….including preventative measures, the promotion of normal birth, the detection of complications in mother and child, the accessing of medical care or other appropriate assistance and the carrying out of emergency measures.” In contrast to this, a doula may be defined as an individual trained to provide continuous physical, emotional and information support to an individual undergoing
varying processes. There are doulas who practice in varying settings and with specific populations—for example, there are death doulas, abortion doulas, and adoption doulas—but in the context of childbirth specifically birth doulas and postpartum doulas are the two most prevalent types of doulas.\textsuperscript{765}

The presence of midwives and doulas on birthing teams has been associated not only with a decrease in maternal mortality but with a decrease in other poor health outcomes such as low birthweight for the baby, a reduction of birth complications, an increase in breastfeeding, and a reduction in unnecessary c-sections.\textsuperscript{766} When considering the impact of including not only Doulas but also Community Health Workers (CHW) to perinatal health teams, there is also a decreased rate of infant mortality, an increase in patient education and knowledge around vital health information, and utilization of prenatal and postpartum care.\textsuperscript{767} Doulas and CHWs may be successful in improving health outcomes due to their ability to provide individualized support and advocacy that tends to the emotional needs of the patient while also helping her maintain a sense of agency and reciprocity in the birth process that is often not found in birthing situations that contain only nurses and doctors.\textsuperscript{768} Davis has also noted that many doulas and midwives center their work through a more justice-grounded framework and, “see reproduction as a site where the inalienable right to have the kind of birth one want should exist.”\textsuperscript{769} This orienting belief means that many doulas and midwives see themselves as explicitly tasked with ensuring that the person giving birth is treated with respect, is a part of the decision-making process for their care, and feels supported, which provides their work with an element of advocacy that is lacking in situations in which they are not present.\textsuperscript{770}

Doulas and CHWs can provide vital advocacy and important continuity of care for individuals navigating the disjointed and often discontinuous systems of care during pregnancy.
and the postpartum period as well as tend to the holistic needs of patients in manner nurses and doctors do not. Moreover, in a context in which many individuals give birth in the presence of teams who they have never met before the day they arrive on labor and delivery, having the support of a doula whose relationship was established prenatally can provide an important element of trust and support in the room. The presence of doulas has also been shown to reduce the impacts of racism and racial bias in health care through “providing individually tailored, culturally appropriate, and patient-centered care and advocacy,” and has for this reason been identified as a key strategy in decreasing rates of maternal mortality for Black women in particular by many advocacy organizations and by Medicaid, the World Health Organization, and professional colleges such as the American College of Obstetricians & Gynecologists.

Doulas, midwives and CHWs are vital members of a multi-disciplinary maternal health team. These teams are needed as a part of a robust restructuring of the way in which perinatal care is organized in this country if we are to improve health outcomes for women and children and reduce maternal mortality.

IV. The Midwifery Model as an Ethics of Care Approach to Maternal Health

In order to help us understand both why outcomes are better when midwives are involved in care and what we can learn about the way in which these professionals view pregnancy and their work to improve maternal care, this section will explore the roles of midwives and how their understanding of their work and of pregnancy can help us provide better, more just care.
a. Midwifery: A Dignity-Enhancing Ethics of Care Approach to Maternal Health

In the context of increasing reports of obstetric violence, unnecessary interventions in childbirth and worsening maternal health outcomes, midwives and the midwifery model of care have been suggested as a solution to turning the tide on poor quality of care and poor health outcomes. Midwifery has been shown to provide highly desired aspects of care that women have identified as lacking in their care otherwise, such as increased agency, a feeling of connection and relationship with their healthcare provider, security, and respect. Midwifery is associated with better patient experience of care, with improved health outcomes for patients such as lower rates of cesarean sections and lower rates of preterm birth, and results in lower costs of care for medically low-risk patients than obstetrician-led care, making it a beneficial service for multiple reasons.

A midwifery approach to care recognizes that while pregnancy and childbirth are processes that the body undergoes on a medical and physiologic level, there are also “personal, social, and cultural meanings that differ across cultural groups” attached to these processes. These additional elements effect individual’s understanding of themselves during pregnancy, their goals and priorities for their care, and their perceptions of their care team. Midwifery is also unique in that it is “a gendered profession that was historically built by women to care for other women, giving rise to an independent body of research and a distinctive care model.” Because of this, and because of the history of exclusionary tactics to remove midwives from obstetric spaces, midwifery and often midwives themselves share in part the experience of not being heard and of feeling disrespected that their patients express feeling in the context of obstetric care.

In a study examining the work of midwives who were integrated into obstetric environments and worked with marginalized communities, researchers found that midwives
prioritized the following five themes as characteristic of their work: “1) the politics of progress; 2) normalizing pathologies; 3) cherished connections; 4) protecting the experience; 5) caring for the social body.” In regards to the first theme, time and caring for patients who were considered laboring “on the clock” was a point of conflict with obstetricians. While midwives emphasize unnecessary intervention and allowing the natural birth process to unfold unless there is a clear clinical reason to intervene, obstetricians prioritize delivering babies as soon as possible, which can lead to tensions and disagreements about whether or not a patient is “progressing” enough. In terms of the second theme, midwives acknowledge that patients who come from communities that are at higher risk for adverse health outcomes and that those patients might need support in understanding that they can still have a positive birth experience even with a higher risk status. In the words of the researchers: “In settings where patients are chronically disenfranchised and burdened by many racial, political and economic inequities, midwives see themselves as being able to promote a wellness approach to pregnancy and birth that should be accessible to everyone—even in the presence of pathology.” This approach can help empower patients, even in the context of complex medical conditions. In regards to the third theme, continuity of care was identified as a top priority, with an ongoing caring relationship being a central component of the care midwives provide. Midwives evaluate their care not only by the health outcomes their patient achieves, but by the quality of their relationship with their patient. In regards to the fourth theme, midwives feel as though it is their job to help protect the experience of birth and advocate for patients to have positive experiences without unnecessary interventions and pathologizing their patients. Finally, the theme of caring for the social body connects the care that pregnant and laboring women receive to their existence in their social experience of health. “The ‘social body’—or the collective process of social construction of
personhood shaped by culture and one’s social milieu” is a critical component of providing care because, “patients do not see themselves as separate or disconnected individual entities.” To care for a human being is to care for her in all of her dimensions, including her social body.

While the obstetric system is, “designed to center measurement, efficiency, and pathology,” the midwifery model of care centers meaningful relationships across the experience of pregnancy and childbirth, respecting, valuing and listening to the individual giving birth, tending to that person as a whole entity and not only a corporeal body, and ensuring the birth as a natural bodily process is allowed to progress without unnecessary medical interventions. Midwifery care is a form of a dignity-enhancing ethics of care approach because it is deeply invested in ensuring that patients are cared for in a manner that honors their personhood and centers their experience of birth as a transformative moment to be celebrated, not pathologized. In additional to the relational elements of the midwifery model of care that aim to tend to the whole personhood of the individual we have already discussed in this section, the dignity-enhancing ethics of care orientation of the midwifery model can also be illustrated through considering the chosen indicators of the Undisturbed Labour and Birth Index developed by the Birth Place Lab. The Undisturbed Labour and Birth Index is still in development and aims to provide a resource for individual birthing facilities to measure the extent to which they are enhancing or diminishing the birthing experience for patients. In considering the indicators that have been selected to help drive improvement efforts related to birthing experience, one can see that these reflect both a relational approach that aims to enhance the dignity of the individual and a responsiveness to the individual in all dimensions of her personhood.

The indicators of the Undisturbed Labour and Birth Index are as follows; “Supportive physical environment, Respectful Maternity Care and Freedom from Mistreatment, Culturally
Safe Care, Access to Midwifery Care, Integration of Care Across Birth Settings, Admission to Hospital in Active Labour, Informed Choice and Person-Centered Decision Making, Continuous Emotional Support, Non-pharmacological Pain Management, Induction and Augmentation of Labour, Freedom to Eat and Drink During Labour, Freedom of Movement and Choice of Birth Position, Fetal Monitoring, Self-directed/spontaneous Pushing During Second Stage of Labour, Cord Clamping, Immediate Postpartum Togetherness, Undisturbed Birth Rate, Breastfeeding Support.” These indicators clearly reflect attempts to promote Nussbaum’s central capabilities as well as the Reproductive Justice commitment to ensuring that the protection of the promotion of these capabilities is extended to those who are most vulnerable. The Midwifery model of care is dignity-enhancing in its prioritization of support for the patient as a whole person within her full, lived context, and its centering of the role that individual relationships play in achieving fulfilling birth experiences supports an ethics of care approach.

b. The Role of Midwives in Reducing Health Inequities for Black Pregnant and Postpartum Patients in the United States

Given that the midwifery model of care is centered on individualized, supportive, relational care that tends to the social, emotional and corporeal needs of individuals, it is well-positioned as a framework to contribute to the reduction of health inequities for Black pregnant and postpartum individuals. Davis has also noted the important role that midwives and doulas can play by utilizing their relational approach intentionally to focus on community engagement, advocacy and education that creates connections between the reproductive needs of specific communities and broader community needs that also need to be addressed; in other words, midwives and doulas are well-positioned to be promoters of reproductive justice in the
communities they serve and the communities in which they live. Midwives are also clearly well-positioned to be advocates for and contribute to birth justice, “the right to give birth with whom, where, when and how a person chooses” and the right to quality care, knowledge about family planning and reproductive services, education about their reproductive health.

While midwives have a crucial role to play in improving health outcomes for pregnant and postpartum individuals and reducing health inequities, they are still having to navigate a broader healthcare context in which they are not always welcome. This outsider status that many midwives—especially Black midwives, experience has at times led to innovative approaches. In the case of Jennie Joseph, her experience of being an Afrolatina midwife led to her creating the JJ Way: a model that prioritizes access to quality care, education, and resources, connections to community, family and providers, patient and patient support education, and empowerment of the individual, their family, and their community as a whole. When evaluated by researchers, the JJ Way model showed an elimination of health disparities in preterm birth outcomes and better maternal health outcomes for women of all races who received services through the model at the Easy Access Clinic and “The Birth Place” birthing center in Orlando. In rejecting the treatment her patients were receiving in hospital birthing settings and creating her own model of care derived from what she perceived to be the needs of families in the communities she served, Joseph was able to transform reproductive outcomes for women, babies, and families alike.

However, not every birth is appropriate for a birth center or home birth, and every patient will not be able to avoid having a birth in a hospital setting. Given this, it is imperative that we continue to work to integrate midwifery into maternal healthcare settings across the country. The Birth Place Lab has created Best Practice Guidelines for Interprofessional Collaboration that lay
out specific best practices for community midwives and hospital providers in order to promote collaborative and health interprofessional relationships. They have also created criteria for midwifery integration and have graded each of the states in the United States on their integration of midwifery into health care systems and provided recommendations for improvement for low graded states. These best practice guidelines and collaboration reports should be taken seriously and acted upon in order to support the change that midwives can bring to maternal health care in this country. Midwives have illustrated their value and effectiveness in improving health outcomes but they cannot have the impact they have the potential to achieve if they are denied access to hospitals, undermined by hospital staff, or silenced when advocating for their patients. Midwives must be fully integrated into health care systems as a key intervention to improve the health and wellbeing of mothers, babies, and communities.

V. Examining the Role of Maternal Mortality Review Committees in Supporting Multi-Disciplinary, Patient-Centered Care

While this chapter has focused primarily on changes that would support improving health outcomes on the level of the healthcare workforce, we will conclude by exploring the impact that Maternal Mortality Review Committees (MMRCs) could play in supporting the movement towards more patient-centered, higher quality maternal health care.

a. The Ethical Need to Adopt a Health Equity Framework in Conducting Maternal Mortality Reviews

As has been discussed throughout this dissertation, maternal mortality rates are disproportionately high for Black pregnant and postpartum individuals. The distribution of
maternal deaths across the United States also differs greatly depending on geographic location, rural vs. urban settings, and state of residence. When it comes to maternal mortality, race, place, socioeconomic status are all factors in how likely an individual is to die during the course of creating a new life. As it currently stands, the dominant approach to reducing maternal mortality has been to identify “high-risk” patients and then provide targeted interventions aimed at preventing more acute or lethal conditions. While this approach is valuable and should not be abandoned, due to the persistent inequities in race across all socioeconomic and geographic considerations, there is concern that this focus on identifying the causes of individual cases of mortality alone may not be sufficient in addressing disparities on a population health level. On the other hand, multi-level responses on the population level may provide insight into the causes of increases in rates within specific populations.

In response to the limited scope of both the individual approach and the population-level approach, researchers have suggested an integrated approach to assessing maternal mortality that, “situates the pregnant woman at the intersection of…her life course social and health trajectory…[and] multileveled causes of reproductive health.” This approach allows us to understand the health and life conditions of individuals on two planes: that of biomedical processes that, “are influenced in part by the timing, quality, and quantity of clinical care as well as health behaviors, which themselves are influenced by constraints and opportunities contained in the community environment,” and the community environment itself, i.e., “the intersection of domains of resources and experiences.” By considering both of these elements in tandem, we are able to assess for both the clinical causes of risk and adverse health outcomes as well as the social and environmental conditions that may have created or attributed to them. Moreover, the mapping of community resources needed to effectively convey the environment in which
individuals live might also provide a better sense of what resources exist and how to expand upon them to create change.

This latter point is significant in the context of Maternal Mortality Review Committees (MMRCs) because these committees are tasked with understanding the causes of death and contributing factors for individuals who have died due to pregnancy-related causes and also create recommendations for policy and clinical priorities at the state level as a result of their investigations. As it stands, the approaches of MMRCs vary widely by state, with some states using only medical documentation to make their assessments and other states using more holistic approaches. This has a major impact on the determinations of the committees, as states who use solely the medical records determined 28% of maternal deaths were preventable, while the range of preventability for states using a more holistic approach varies from 40%-70%. This increase in determination of preventability reflects a view in which women are not only, “isolated patients but also…members of a larger environment replete with exposures and opportunities.” By considering patients within this broader context, “upstream health service, social and environmental determinants of health may be conceived of as underlying contributors to a biomedical cascade of events ending in a tragic death.” Applying a health equity framework to reviewing maternal deaths allows us to see the fuller picture of a woman’s life and of her death. This will allow us to identify more points of intervention and can expand the scope of recommendations from MMRCs and has the potential to prevent continued increases in maternal mortality rates.
b. An Argument for the Inclusion of Ethicists in Maternal Mortality Review Committees

A potential barrier to implementing the health equity framework described in the previous subsection that has been raised by the creators of the framework themselves is the concern that MMRC committee members may see social determinants and community-based causes as falling outside of their immediate sphere of influence, due to the majority of these committee members coming from hospitals and health systems. While it is admirable that obstetricians and health systems have coordinated many of the recent efforts on the state level to reduce maternal mortality, the fact of the matter is that the majority of pregnancy-associated deaths occur during the postpartum period and during pregnancy, and not when individuals are giving birth at the hospital. While obstetricians and hospitals need to continue to examine the role that they can and should play in improving hospital care and preventive services in outpatient healthcare clinics, the overall community that is invited to the table to identify and address causes of maternal death needs to be expanded. Community-based organizations and community advocates have been fighting to improve maternal health outcomes for decades before obstetricians and health systems were willing to admit that there was a need. The causes of maternal mortality expand far beyond the walls of hospitals and outpatient clinics, and experts who understand the environments and conditions in which individuals from high-risk communities live should be involved in assessing factors contributing to death as well as the conversations surrounding statewide recommendations.

Another important voice that should be at the table of MMRCs but is largely absent are the voices of medical ethicists. Ethicists are trained to assess situations for their ethical dimensions, understand and interrogate opposing viewpoints, and make recommendations for action as a result of their inquiry. For these reasons, ethicists are ideal contributors to MMRCs,
not only because they possess the facilitation and mediation skills to help committees navigate potentially heated discussions but because the discussion surrounding both the situations that led to pregnancy-related deaths and the determination of statewide recommendations should have a clear element of their ethical dimensions considered. While doctors, nurse managers, and other clinical staff that tend to comprise MMRCs are certainly not lacking in ethical beliefs and moral attitudes, having an ethicist contribute to MMRC discussions with the explicit and sole purpose of providing ethical considerations to the deliberations taking place would result in more robust discussions of the causes of death and recommendations that place a greater emphasis on moral responsibility in their approach.

Conclusion

To provide care that is truly responsive, we need to be attentive to the needs of not only the two members of the mother-baby dyad but to the social and environmental conditions that support or deny them health. This entails supporting mothers who are susceptible to harm, such as those who are experiencing substance use disorders in pregnancy, through comprehensive, non-punitive, wrap-around approaches to addressing their needs and the needs of their child, coming to terms with the racist and sexist foundations of obstetrics and gynecology, and creating better cultures in medical education and health care environments that support diverse communities. This also involves broadening our understanding of who is a member of our maternal health teams. Doulas, midwives, CHWs, and patients and family members alike are all vital team members with invaluable roles to play in creating safe and responsive care. This also involves widening our understanding of who needs to be at the table to understand and address negative health outcomes. We live our lives in communities, and we will only begin to address
the unacceptable health outcomes of our mothers and children if we begin to interrogate and propose solutions as a community.
Chapter Seven: Conclusion

*Any real change implies the breakup of the world as one has always known it, the loss of all that gave one an identity, the end of safety*

...*what we are struggling against is that death in the heart which leads not only to the shedding of blood, but which reduces human beings to corpses while they live*

- James Baldwin

Octavia Butler once wrote, “there is nothing new under the sun. But there are new suns.” Within a cultural context in which proponents of technological advancements preach the ability of the next new inventions to save us all and “fix” inequalities, I ask you to consider, not something new, but a reorientation. This reorientation would entail the creation of new systems of care, new methods of undergoing and evaluating our caring efforts, and the expansion and creation of new communities. However, these should be thought of not as new solutions that will inherently change the status quo, but as the result of and process through which we accept responsibility for the duties we have to care for one another.

Efforts to improve care in healthcare that have centered around safety have failed not because safety is an inadequate foundation, but because the conception of safety at their center constitutes a lack and not a positive vision around which to organize. The safety to which we strive should not entail merely preventable death or harm to a patient, but a living, breathing process in which the relationships between patients, families, and caring teams enhance the inherent dignity of each individual and contribute to the overall flourishing of both individuals
and their communities. Reactive policies that arise out of risk aversion-based approaches to safety will never result in human flourishing because that is not what they are designed to do. Avoiding error does not entail providing safety. When a positive conception of safety is adopted, safety as an orienting and foundational concept around which to organize our systems of care allows us to understand both the role that individual caring relationships play in the extent to which people receive and provide care but also the structural components that enhance, detract from, or thwart our caring efforts.

When considering ways through which safety can be experienced, a dignity-enhancing ethics of care approach that has its normative foundations in reproductive justice and promoting fundamental capabilities provides a positive framework through which to address both individual and structural aspects of care, while also explicitly addressing the current power dynamics that result in racist and inequitable distribution and quality of care. This dissertation has considered the adoption of this approach in the context of maternal health both because the creation of and entrance of new life into the world is a vulnerable period that has wide-reaching consequences for parents, children, and communities, but also because the current state of maternal health in the United States exemplifies the extent to which our current conception of safety and our current systems of care have failed.

To turn the tide on the rising negative health outcomes for pregnant and postpartum individuals that has inequitably impacted socially disempowered communities, we need to shift the focus of our efforts from increasing receipt of individual services that healthcare providers have deemed as significant to listening to individuals and communities when they express their priorities for and experiences of care. Many of the needs of individuals and of communities are not met through our current caring methods because they are not seen or acknowledged by our
current methods. Trusting, robust caring relationships and systems of care are built upon a foundation of moral attentiveness, which requires co-creation and collaboration in order to ensure that needs are being fully understood and adequately addressed.

This foundation of moral attentiveness requires a reconsideration of responsibility in the context of caring. In order to make strides in both improving aspects of care over which they have direct control and improving overall health outcomes, individuals and organizations across systems of care must first understand the aspects of care for which they are responsible and how their role in the process of care relates to the broader systems of care of which they are a part. Meaningful collaboration and continuity of care requires communication throughout the entire caring process so that parties can understand their responsibilities at any given point in time and how those responsibilities support or hinder the overall health of individuals. In maternal health, this emphasis on the broader systems of care as a whole must entail the de-centering of hospital teams as the primary locus of improvement of care and the explicit connecting and strengthening of relationships between in-patient, outpatient, and community-based settings of care.

The understanding and assignment of responsibilities must be supported by reimbursement strategies that not only enable quality and equitable treatment, but encourage and require it. Quality measurement, quality improvement, and healthcare reimbursement strategies should hold the long-term positive health of the patient as their overarching goal, and the ways in which we measure our success should be oriented around achieving this overarching aim. This shift will require not only the inclusion of qualitative data and patient narratives in developing improvement strategies but an expansion of what services are included under the umbrella of healthcare to include vital care such access to transportation, food and housing support, and other community-based resources.
Performing our responsibilities to care for new and growing families will also require us to become more explicitly and intentionally responsive to the needs of the maternal side of the mother-baby dyad. In previous decades, the health of mothers has been considered as secondary to that of their child and in the context of women whom society has deemed “unfit” to have children or “bad mothers,” the potential of harm to the child has been used to demonize and criminalize mothers with chronic, persistent health conditions such as Substance Use Disorders, while also contributing to creating barriers to needed treatment and accessing other needed resources. Providing truly responsive care to the dyad necessitates a more holistic understanding of maternal health to include behavioral health needs and social and environmental factors that can help or hinder the health of mothers and babies alike. More responsive care also necessitates the separation of accessing and receiving health care for health conditions from criminal and legal systems when there is no clinical or evidence-based reason for their involvement. Punitive policies have been proven to provide a barrier to accessing treatment and result in poor health outcomes for mothers and their children. Providing responsive care that supports the overall health of mothers and recognizes behavioral health conditions as health conditions and not as criminal or legal violations allows mothers to receive the help they need while also preserving the therapeutic relationship with their healthcare team.

By recognizing that all pregnant and postpartum individuals are human beings outside of and in addition to their status as a mother, we can better tend to them as whole individuals, which in turn will support their overall health and the health of their children. By recognizing that the lives of parents and children are deeply impacted by the communities and environments in which they live and that, in turn, their lives have a profound impact on the health and wellbeing of their
communities, we can better explore the ways in which individual health and community health are intertwined and can become more mutually supportive.

Van Rensselaer Potter famously stated that global bioethics should be a bridge: a bridge between present and future, a bridge between science and values, a bridge between nature and culture, and a bridge between man and nature. As human beings, we are constantly “connected and connecting” to each other and our environment in the role of bridge builders, and our ethical concepts should be dynamic aides in helping to connect different aspects of the world to one another. This conception of bioethics is one that inherently involves a process of dialogue, reflection, and revision. Building bridges requires architects and visionaries, but also physical labor, consideration of and responsiveness to the environment in which one is building, and the adaptiveness to change if the blueprint goes awry. Above all, however, this conception of bioethics requires collaborative imagination that links our current conditions to an image of the future in which human beings have survived and have achieved longer-term goals towards happiness and human flourishing.

This dissertation should be considered an invitation to collaboratively imagine what a blueprint for a bridge to healthier families and healthier communities might look like. It begins with a consideration of the impact that an ethics of care and reproductive justice approach to safety might have on maternal health in particular, but, as should be evident from the preceding chapters, maternal and child health is inherently linked to and dependent upon wider systems of care. Pregnancy and the postpartum period are unique and significant moments in the life of an individual, but they are only a short period of time within a much longer lifespan. To more fully imagine what our systems of care could entail and accomplish, we need to imagine concrete ways in which we can connect and enrich our systems of care before pregnancy and after the
postpartum period as well. This reflects an essential aspect of reproductive justice itself: justice and liberty are fundamental and should be protected across the lifespan and across generations. And in our current moment, human rights are denied and inequities exist across the lifespan and intergenerationally as well.

Human flourishing entails that the individual is able to live to their fullest potential. This potential may look different for each individual and each community, but it requires, at minimum, that one can live a life that they consider meaningful, in relationship with others. While this bare minimum might seem easily achievable at face value, the persistence of racial injustice, vast social and economic inequities, and the denial of basic environmental necessities such as clean drinking water, breathable air, and protection from the elements have placed communities and individuals in contexts in which their ability to flourish and the future they are able to imagine for themselves are shaped in inequitable ways rooted in injustice. In order to imagine a future in which children, families, and communities can flourish, we must all understand the role we have to play in envisioning and building bridges to that future. To return once more to the words of Octavia Butler: “all that you touch/You Change./ All that you Change/Changes you.” We all have a responsibility to change our current methods and systems of caring. And in turn, by participating in that change, those changes we create will change us, and our children, for the better.
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