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Social and Biological Determinants of Pregnancy-Related Mortality and Morbidity in a Rural, Underserved Population

Anna Hansen
University of Kentucky, anna.hansen@uky.edu
Author ORCID Identifier:
https://orcid.org/0000-0002-7344-2825
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Anna Hansen, Student

Dr. Carrie Oser, Major Professor

Dr. Janet Stamatel, Director of Graduate Studies

SOCIAL AND BIOLOGICAL DETERMINANTS OF PREGNANCY-RELATED MORTALITY AND MORBIDITY IN A RURAL, UNDERSERVED POPULATION

DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
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at the University of Kentucky

By
Anna Christine Hansen
Lexington, Kentucky
Co- Directors: Dr. Carrie Oser, Professor of Sociology
and Dr. Mairead Moloney, Professor of Sociology
Lexington, Kentucky
2022

https://orcid.org/0000-0002-7344-2825

ABSTRACT OF DISSERTATION

SOCIAL AND BIOLOGICAL DETERMINANTS OF PREGNANCY-RELATED MORTALITY AND MORBIDITY IN A RURAL, UNDERSERVED POPULATION

Cases of severe maternal morbidity (SMM) and pregnancy-related mortality (PRM) are increasing in the US. Research concerning SMM and PRM has neglected women in Central Appalachia; a largely rural, health-disparate population. The aims of this study are two-fold: (1) Examine patient-level and place-based predictors of SMM/PRM via hierarchical logistic regression modeling, and (2) Elucidate Appalachian healthcare patients' and providers' experiences with SMM/PRM, perceptions of contributing factors, and insights on points of intervention.

This study uses a mixed methods approach guided by the WHO's conceptual framework for action on social determinants of health to identify determinants of SMM and PRM among Appalachian women. Aim 1 involved hierarchical logistic regression modeling to assess patient-level and regional predictors of SMM and PRM using the MarketScan Research Database. Aim 2 involved 30 qualitative interviews with Appalachian participants: 10 patients with histories of SMM, 10 providers, and 10 emergency medical technicians (EMTs).

Quantitative results demonstrate patient-level chronic diseases and regional measures of economic security as predictive of SMM. Qualitative results echoed the effect of regional economic hardship on maternal health. Participants expressed a link between changes in the socioeconomic landscapes of their communities and more proximal determinants of maternal health, including patient nutritional status, chronic disease burden, and underutilization of healthcare. Patients with histories of SMM pointed to geographic constraints in healthcare resources and biases within healthcare surrounding patients' reflections of class. Participants identified many points of intervention, including collaborations between EMS and obstetric care providers, partnerships with local school systems to introduce comprehensive health education curricula, and expansion of community paramedics programs.

Findings warrant further investigation into how regional economic policy may influence maternal health outcomes among women living in economically insecure regions. Findings highlight the need for medical stewardship. Additionally, results reflect

how current care-delivery models for medically and socially complex patients may be inadequate for women in rural communities.

KEYWORDS: Maternal health, health disparities, health equity, rural health, Appalachia

Anna Christine Hansen

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Date

SOCIAL AND BIOLOGICAL OUTCOMES OF PREGNANCY-RELATED MORTALITY AND MORBIDITY IN A RURAL, UNDERSERVED POPULATION

By
Anna Christine Hansen

Dr. Carrie Oser
Co-Director of Dissertation

Dr. Mairead Moloney
Co-Director of Dissertation

Dr. Janet Stamatel
Director of Graduate Studies

4/14/2022
Date

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CHAPTER 1. AN INTRODUCTION TO DISPARITIES SURROUNDING MATERNAL MORBIDITY AND MORTALTIY IN THE UNITED STATES

1.1 A Case Study of Severe Maternal Morbidity in Appalachian Kentucky

At the time of presentation to her local emergency department (ED) in Appalachian Kentucky, Grace[I] was a 28-year-old gravida-5 para-4 woman at thirty-seven weeks gestation with spontaneous rupture of membranes. Following her arrival to the ED for labor, she was admitted to the local hospital's labor and delivery unit. Several hours later, she had a spontaneous vaginal delivery of a healthy, term baby girl. Immediately following delivery, she experienced a cardiac arrest. She is unable to report further details of her delivery hospitalization until one week later, when she was extubated from mechanical ventilation.

Upon her arrival to the ED for labor, Grace endorsed significant dyspnea, bilateral lower extremity edema and generalized fatigue of several months duration. Her symptoms had progressively worsened as she neared term. She had presented to the same ED for dyspnea two days prior to her delivery at the insistence of her mother. She had found the provider's assurance that her symptoms were attributable to a healthy term pregnancy insufficient. However, at this time she returned home, and did not seek further care for her symptoms prior to the onset of labor. Grace received all of her prenatal and obstetric care at a 150-bed hospital in her rural hometown in eastern Kentucky. Although she considered

[I] Grace's experiences reflect the narrative of one study participant. Name and identifiable details are altered to protect the identity of participants.

seeking care at another institution, she resolved to remain at home; the distance to another clinic was prohibitively far, and her symptoms were prohibitively severe.

Grace's past medical history is significant for opioid use disorder (OUD). She received long-term medication treatment for her OUD through a local suboxone clinic. She reports her prenatal care providers worked in close contact with this clinic to continue medication for OUD treatment. To Grace, her cardiac complications were both frightfully unforeseen and deeply intertwined with her history of OUD. She denied significant maternal or fetal complications with her prior four pregnancies.

1.2 An Introduction to the Topic

Throughout Appalachian Kentucky, obstetric patients and providers convey stories of rapid decompensation and near-misses with mortality. Several counties to the northeast of Grace, an emergency medical technician (EMT) recalled transporting a woman with disseminated intravascular coagulation who delivered at home, and "almost bled to death" while en route to the nearest hospital with local emergency medical services (EMS). Still farther to the east, a physician recalled a post-partum patient who collapsed while alone at home with her newborn – the consequence of untreated severe anemia and post-partum blood loss. Mothers, providers, and EMTs alike relayed stories of confusion and complexity, attempting to articulate why problems arose, and moreover, how they could have been prevented.

In this dissertation, I seek to understand the factors, circumstances, and personal narratives that account for maternal morbidity (and sometimes mortality) among some of the most vulnerable women in the US, those living in central Appalachia. This introductory

chapter presents the following: (1) maternal mortality in the American public eye, (2) operationalized definitions of maternal morbidity and mortality, (3) past emphases on patient-level risk factors when studying maternal morbidity and mortality, (4) challenges in accounting for social context, (5) maternal morbidity and mortality in the rural US, (6) risk factors for poor maternal pregnancy outcomes in Appalachia, and (7) the need to reconceptualize a preventable maternal death. This chapter ends by introducing (8) the conceptual framework utilized by this study and (9) a project overview.

1.3 Operationalizing Measures of Maternal Mortality

Grace's experience at delivery is striking, yet far from unique. Grace is one of the estimated 50,000 American women who experience severe maternal morbidity (SMM) at delivery; who, had she not received swift cardiac resuscitation, would have faced pregnancy-related mortality (PRM). The Centers for Disease Control and Prevention (CDC) and the World Health Organization define PRM as the death of a woman during, or within one year of pregnancy, due to a pregnancy complication, a chain of events provoked by pregnancy, or an aggravation of a preexisting condition.[1] SMM is defined as the occurrence of end-organ damage in the mother, and encompasses unexpected outcomes of labor and delivery, resulting in significant short- or long-term consequences to a woman's health.[1] The CDC definition of SMM encompasses 21 distinct diagnoses and procedures, including events such as an acute myocardial infarction or respiratory ventilation.[1] PRM provides an operationalizable definition for maternal mortality, and SMM provides a definition through which cases of near-miss mortality may be examined.

Although vast progress has been made over the last 100 years, the number of women dying from pregnancy-related causes in the US began to rise around the turn of the 21st century and has since nearly doubled, and cases of SMM have nearly tripled.[1, 2] Approximately 700 women die every year from pregnancy related causes, and an estimated two-thirds of these deaths are deemed preventable.[3] While this number is dwarfed by other leading causes of death, the preventable nature of most PRM cases,[3] significant and persistent disparities,[3] and dramatic impact of PRM on family and community wellbeing[4] elevates the importance of this phenomenon. Women who experience SMM have a nearly 400 times higher risk of dying from pregnancy-related causes compared to women with no SMM, indicating the need to identify factors predicting SMM and SMM progression to PRM.[5]

The burden of SMM and PRM is reflected not only in patients, but in costs that afflict families and strain systems. In deliveries with multiple severe maternal morbidities, the cost of hospitalization on average climbs from $4,300 to greater than $50,000, translating to aggregated costs of more than $630 million per year.[6] Overall, since the turn of the century, families in the US have experienced hundreds of thousands of preventable obstetric morbidities, thousands of maternal deaths, and billions of dollars of healthcare costs.[6] In the following paragraphs, I examine the known risk factors contributing to this burden of disease and death.

1.4 An Epidemiological Emphasis on Patient-Level Risk Factors

Although pregnancy-related death has increased across all demographics of women in the US, not all subpopulations are equally affected.[1] Obstetric literature has abounded

with analyses attempting to predict which patients are at greatest risk when considering individual demographics and medical histories. Intuitively, poor health prior to the conception of pregnancy is associated with poor health during pregnancy and poor maternal outcomes.[7] Past population level analyses have demonstrated an increased risk for SMM and PRM among women with common chronic illnesses, including hypertension, pre-existing diabetes and chronic heart, renal, and liver diseases.[8]

A multitude of other individual health behaviors and demographic factors have been tied to SMM risk. Substance use and smoking status both increase the risk of SMM.[9] Both low and high Body Mass Index (BMI) measures are associated with increased risk of SMM.[10] Advanced maternal age is consistently associated with SMM and PRM, with greater age conferring greater risk.[11]

Disparities surrounding race and ethnicity are stark and consistent. Black women in the US are three to four times more likely to die from pregnancy-related causes compared to white women, and are more likely to die from causes deemed "preventable." [2, 12, 13] Among high-risk pregnancies, Black women are 9.9 times more likely to die than white women with the same complications.[13] Of particular concern is disproportionate risk of cardiomyopathy, thrombotic embolism, and hypertensive disorders of pregnancy (e.g. eclampsia). Similar trends are present in the study of SMM; Black women experience SMM at delivery at twice the rate of white women, and are more commonly diagnosed with twenty-two of the twenty-five severe diagnostic indicators.[13, 14] Past studies have also found American Indian and Alaska Native women to be approximately three times as likely to die from causes attributable to pregnancy compared to white women, with particularly concerning rates of hemorrhages and hypertensive disorders.[13]

1.5 Challenges in Accounting for Context

The aforementioned studies have expressed the association between maternal outcomes and patient-level risk factors. Additional studies have attempted to situate patients within a clinical context. Hospital-level variables have been found to significantly predict poor maternal outcomes. Deliveries with SMM were more often in hospitals that serve minoritized populations and are located in the Southeastern United States.[15] Some studies have demonstrated that the effect of hospital-level risk factors supersedes patient-level predictors; a 2016 study by Howell and colleagues using the National Inpatient Sample examined the concentration of delivery care for Black women.[16] Researchers found that one-quarter of hospitals provided care for three-quarters of all Black deliveries in the US. Hospitals that disproportionately delivered Black patients had higher SMM rates after adjustment for patient and hospital characteristics.[16] Findings suggested the racial breakdown of the hospital, rather than the racial identity of a single patient, predicted poor outcomes.

Several past studies have looked beyond the hospital, and discussed the implications of socioeconomic position. In 2017, Admon and colleagues estimated the prevalence of eight common chronic conditions associated with SMM and PRM.[8] Differences over time were measured and compared across rural and urban residence, income, and payer subgroups. The prevalence of chronic conditions increased across all segments of the childbearing population. However, increasingly wide disparities were identified, in which chronic diseases disproportionately burdened rural and low-income women. The widening economic disparities in health status suggest it is increasingly important for providers to understand the socioeconomic context in which childbearing live.

However, some previous research examining contextual factors for SMM risk have not demonstrated significant associations.[17] A 2018 statewide study of delivery hospitalizations in New York modeled patient- and hospital-level factors alongside local contextual factors, including density of obstetric providers, median household income, unemployment rate, proportion of food stamp beneficiaries, phone accessibility, and other statistics concerning morbidity and mortality.[17] Findings served to confirm the associations between patient-level predictors and SMM, and the authors endorsed SMM prevention efforts should target individual risk factors, and deemphasized the impact of broader community inequities. Such findings provide complex insight concerning the influence of patient, provider, hospital, and community characteristics on the prevention of SMM and PRM.

1.6 SMM and PRM in Rural Populations

Rural communities are in part defined by unique strengths, including resilient community relationships attributable to long-standing residency.[18] Despite such strengths, rurality has also been considered in some instances a social determinant of poor health outcomes.[19] Namely, rural communities face disproportionate disease burden and an all-cause mortality penalty.[19] In 2016, the mortality rate in rural, low-income America was an estimated two decades behind mortality patterns of urban communities.[19] Disparities are largely driven by rural counties with high rates of poverty.[19]

Disproportionate burden of morbidity and mortality in rural communities is reflected in high rates of SMM and PRM. Research conducted by the PI of this study and committee members have demonstrated rural women in the US to be at elevated risk for PRM and

SMM.[11, 20] Rural pregnant women in the US experience higher rates of chronic illnesses including hypertension, non-gestational diabetes, and substance use disorders compared to their urban counterparts.[8] Growing disparities in chronic illnesses disproportionately and increasingly impact low-income women and rural women.[8] Past studies indicate a significant association between rural residence and SMM, including life-threatening diagnoses of eclampsia, obstetric embolisms, and uterine rupture.[5]

Rural women face unique geographic constraints related to PRM and SMM, including limited healthcare resources, hospital closure, and isolation. High-quality prenatal care and access to specialized obstetric care alleviate risk of SMM and PRM.[21] Compared to women in metropolitan areas, rural women have reduced access to prenatal care,[22] enter into prenatal care at a more advanced stage of pregnancy,[23] and are at a greater risk for delivery complications and poor pregnancy outcomes, including SMM.[5, 24]

Focus on rural women is particularly salient considering the changing landscape of rural obstetric care. Accessibility of obstetric care in rural areas is worsening, and rural communities are facing a decline in hospital-based obstetric services.[25, 26] A national survey demonstrated approximately half of rural hospitals do not provide obstetric care.[26] Of hospitals located in noncore rural counties (i.e. population less than 10,000), only one-quarter provided maternity care.[26] Closure of hospitals and hospital-based obstetric units is associated with an exacerbation of maternal health disparities in rural areas, including decreased utilization of prenatal care, increased out-of-hospital births, and increased births in hospitals without obstetric units.[21] Between 2004-2014, the percent of rural hospitals with obstetric services fell from 54% to 45% due to hospital and obstetric unit closures.[25]

The decline in noncore rural counties was especially severe, at three times the rate of closures in micropolitan counties.[25]

Pregnant patients are exposed to an increased risk for morbidity and mortality when delivering in locations where clinicians do not regularly manage obstetric patients, indicating that deliveries outside of hospitals with obstetric units may exacerbate pregnant women's risks for poor outcomes.[21, 27] The closure of hospitals in rural areas shifts risks associated with obstetric management from the hospital setting to local clinic staff and emergency medical technicians (EMTs), who may not be equally equipped to provide obstetric care.[21] Women who give birth close to home in areas lacking in hospital-based obstetric care require substantial unanticipated clinical support from nearby hospitals, clinics, and EMTs.[21] A national survey of rural hospitals that do not routinely offer delivery services found 32% reported adverse birth outcomes in the past year, 22% reported a delay in urgent transport of a pregnant patient, and 28% reported a delivery within the emergency department.[28] Furthermore, living in rural areas can complicate access to advanced obstetric and post-natal care, increasing the risk of SMM.[5]

Some of the challenges facing rural women are mirrored in other minoritized populations with disproportionate burdens of SMM and PRM, while other challenges remain distinct. Similar to rural women, Black women and Indigenous women across the rural-urban spectrum experience a high burden of preexisting comorbidities at the time of pregnancy, predisposing them to morbidity and mortality.[29, 30] Additionally, Black women in suburban and urban areas also experience challenges surrounding access to family planning services and prenatal care.[31] However, these barriers to care are not attributable

to geographic isolation or nearby hospitals capability, indicating rural populations face distinct constraints with respect to healthcare resources.

Rural populations across the US encompass diverse populations with respect to race and ethnicity. Rural Black women face increased risk for poor perinatal outcomes compared to both rural white women and urban Black women.[18] Challenges in obstetric care access may be especially dire for Black rural women; closures of rural obstetric units are more likely to occur in hospitals with majority-Black patient populations.[32] Rural Indigenous American women also face higher rates of SMM and mortality compared to both urban indigenous women and rural white women.[29] These patterns indicate the need to address the intersection of race and place-based maternal health inequities.

1.7 Poor Maternal Pregnancy Outcomes in Appalachia

The effects of rurality on maternal health materialize in Appalachia, a region in which 42% of the population lives in a rural area (compared to 20% nationally).[33] Appalachian women of childbearing age are in poorer health prior to the conception of pregnancy, including higher rates of smoking, obesity, and poor nutrition compared to their non-Appalachian counterparts.[7] Appalachian women of childbearing age also report lower rates of health insurance, and lower rates of annual check-ups with healthcare providers, which further expose them to poor pre-conception health.[7] Rural Appalachian women have sparse resources with respect to detection of risks during prenatal care and delivery of emergency obstetric care when complications arise. Availability of specialty physicians, including obstetricians and high risk maternal-fetal specialists, is 65% lower in rural and economically distressed areas of Appalachia compared to the country as a whole.[34] These

disparities indicate critical barriers exist concerning proper risk assessment and crisis management.

1.8 Redefining a Preventable Death

Central to national discussions of maternal mortality is the concept of preventability. Between half and two-thirds of PRM cases in the US are deemed preventable.[35-37] The implication behind this statistic is the remaining half of PRM cases are inevitable, and not subject to influence by evidence-based intervention. Further evaluation of the meaning of preventable PRM is necessary to understand the role of future intervention.

In an early statewide review of maternal deaths in 2005,[37] Berg and colleagues examined each pregnancy-related death for potential mechanisms of prevention. This study defined four categories of preventable PRM: (1) pre-conception care, in which women should have received counseling concerning a severe risk for pregnancy complications given known preexisting medical conditions; (2) patient actions, in which patients did not adhere to medical advice, refused necessary treatment, or failed to seek care in a timely fashion; (3) system factors, in which the overall functioning of the health care system resulted in non-optimal care; and (4) quality of care, in which the care provided to the patient fell below the expected standards given the level of the facility.

In congruence with more recent studies,[2, 13, 14, 16, 38-41] Berg et al demonstrated significant race-based disparities. Among Black women, 46% of deaths were deemed preventable, compared to 33% of deaths in white women. However, when removing cases deemed preventable from counts of PRM, the rate of pregnancy-related death remained three times higher among Black women when compared to white women in the state.[37]

According to Berg et al's findings, racial disparities in PRM were unpreventable; if the medical community avoided all preventable maternal deaths, Black American women would still continue to die from pregnancy-related causes at a higher rates than white women. Such implications are unfounded, and reflect a limited scope of prevention efforts. There exists no inevitable reason for race-based maternal disparities.[42] All deaths reflecting racial disparities in maternal health are ultimately preventable, and moreover, inequitable.[43]

Underlying these findings are broad implications for deeper evaluation for the meaning of preventability. Berg's classification of preventable PRM captures clinically preventable deaths. From pre-conception to post-partum care, Berg identifies underlying causes of death attributable to the patient, provider, and healthcare system.[37] These classifications are informative yet far from sufficient, as they rely upon limited definitions of preventability. Importantly, these classifications do not account for longstanding structural inequities that predispose certain populations of minoritized women to poor health long before the conception of a pregnancy. Reconceptualizing preventability to include both clinically and socially preventable deaths is essential to alleviating maternal health disparities.

Maternal Mortality Review Committees (MMRCs) have adopted similar definitions of preventability to Berg and colleagues.[44] MMRCs existed throughout the twentieth century, waning in the 1990s when maternal mortality reached a national low, and resurging in the mid-2010s as death rates and public awareness reached new highs.[44] Beginning in 2019, the CDC initiated programming for Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM), which now funds statewide MMRCs in 31 states. Comprised of multidisciplinary members including medical

specialists, epidemiologists, and patient advocates, MMRCs review maternal deaths on a case-by-case basis. MMRCs vary widely in their estimations of preventability.[45] Variation corresponds in part to the make-up of committee members and the data available on each patient case. Committees solely reliant on medical record information estimate rates of preventability as low as 28%, while committees with more holistic data and larger MMRC resources report rates as high as 70%.[45] Such findings indicate that preventable deaths may be under-estimated by MMRCs who lack the social context surrounding PRM cases, such as the patients' socioeconomic position and greater socioeconomic and political contexts.[45]

Health equity leaders in obstetrics have called for MMRCs to incorporate a multileveled, theory-grounded framework when reviewing cases that accounts for the social context in which women live, work, and seek healthcare.[45] Yet, interpretation of preventability remains varied, and separate MMRCs may interpret the same case as both preventable and unpreventable.[46] Furthermore, reconceptualizing preventability has implications extending beyond the walls of an MMRC conference room. Understanding a death as preventable or unpreventable has implications for all actors in a pregnancy, including patients, families, clinicians, and researchers.

The definition of preventability used by Berg and adopted by MMRCs limits itself to the clinical realm. It does not account for the social conditions in which patients, providers, and healthcare systems function. Unearthing and accounting for social conditions may provide context for classifications of clinically preventable deaths (e.g., *Why do patients not adhere to medical advice, refuse necessary treatment, or fail to seek care in a timely fashion? Why may the care provided to a patient fall below expected standards?).* Social conditions may also provide a novel lens through which to reexamine

preventability (e.g., *Can distal social factors account for cases of mortality previously deemed unpreventable? Can such factors be modified to alleviate maternal health disparities?*). Reconceptualizing preventability to include both socially and clinically preventable deaths has implications not only for racial disparities, but for all cases of PRM. Accounting for structural determinants of health inequities invites interventions to engage with patients' social context and introduces novel points of intervention outside the clinical realm.

1.9 The Conceptual Framework for Action on Social Determinants of Health

1.9.1 Overview

This study utilizes the conceptual framework for action on the social determinants of health adopted by the World Health Organization (WHO) Commission on the Social Determinants of Health (i.e. the CSDH framework), which seeks to highlight distinct levels and mechanisms of causation resulting in health inequity (Figure 1.2).[47, 48] This framework identifies social contexts, differential vulnerability, and differential consequences experienced by patients.[48]

1.9.2 Structural Determinants

The CSDH framework theorizes social, economic, and political mechanisms (i.e., socioeconomic and political contexts) stratify populations according to income, educational attainment, occupation, gender, race/ethnicity, and other factors. The resulting socioeconomic positions impact intermediary determinants of health status. Based on their socioeconomic position, individuals experience different exposures and vulnerabilities to poor health outcomes. Furthermore, the CSDH framework posits a feedback mechanism in

which poor health in turn impacts socioeconomic position, such as by restraining individual's opportunities for employment, income, or education. The CSDH framework also posits the potential for widespread and epidemic diseases to affect social contexts via political institutions, social and economic policies, and cultural values.

1.9.3 Intermediary Determinants

Structural determinants of health inequity operate through intermediary determinants to impact health outcomes. Namely, the CSDH identifies material circumstances, individual health behaviors, biological risk factors, and healthcare system factors as intermediary determinants. When judging the preventability of a maternal death, MMRCs have historically focused on intermediary determinants, such as comorbid disease states, healthcare utilization, and patient management upon presentation.

1.9.4 Applying the CSDH Framework

The CSDH framework has proven highly applicable to the examination of maternal health disparities. A 2020 systematic review uses the CSDH framework to synthesize current literature on the social determinants of maternal mortality in the US, and identify potential areas of clinical and public health interventions.[49] This review identifies a sparsity in studies examining the socioeconomic and political context, or area-level predictors. The relationship between these structural constructs and disparate rates of SMM and PRM is identified as a crucial gap in current literature. Additionally, few studies were found to explore causal pathways between social determinants and maternal health disparities, and how structural and intermediate determinants influence one another to impact disparate health outcomes. Lastly, minimal attention has been paid to regional differences in maternal health outcomes within the US. Studies examining place-based characteristics

have not focused on rural communities, but rather densely populated areas, such as New York City.[50]

This dissertation seeks to address these limitations. Specifically, this study utilizes the CSDH framework to examine understudied structural constructs, as well as the interplay between structural and intermediary determinants. Additionally, this study focuses on an understudied and underserved patient population within a distinct region.

This dissertation utilizes the CSDH framework is in two distinct ways. First, the CSDH framework informed the inclusion of variables within hierarchical logistic regression modeling described in Chapter 2. Hierarchical regression modeling facilitates the inclusion of place-based structural determinants of health (e.g., measures of regional economic security) alongside intermediary determinants (e.g., a patients' preexisting comorbidity). Second, the CSDH framework informed the development of qualitative interview questions with Appalachian patients, providers, and emergency medical technicians. Through qualitative interviews, participants discuss the role of both intermediate and structural determinants as they identify factors contributing to SMM and PRM in their communities, and how these factors affect with one another. Additionally, participants discuss possible intervention efforts that may modify these determinants.

1.10 Project Outline

1.10.1 Project Overview

This dissertation elucidates intermediary and structural determinants of SMM and identifies points of intervention for SMM and PRM prevention among pregnant and postpartum women, with particular focus on women in Central Appalachia. Evaluating and

improving health of pregnant and postpartum women is an important public health priority. The CDC, the American Medical Association, and the American College of Obstetrics and Gynecology have called upon researchers to further elucidate medical causes and social determinants of SMM and PRM.[1, 51, 52] Furthermore, the National Institute for Child Health and Human Development lists improving health of women before, during, and after pregnancy; and improving pregnancy outcomes as high-priority areas of research.[53] This study responds to calls of these leading national institutions, who seek more information concerning predictors, and social determinants of SMM and PRM. Findings may inform the development of evidence-based, culturally competent interventions among this population. This dissertation uses a three-manuscript format, with distinct papers comprising the second, third, and fourth chapters. Each paper is briefly described below in terms of its aims and data sources.

1.10.2 Chapter 2, Manuscript 1

This study begins by robustly assessing social determinants of health as risk factors for SMM via hierarchical logistic regression modeling. Both patient-level and regional predictors of SMM are assessed. Particular attention is paid to structural and intermediary predictors of SMM, as informed by the CSDH framework. In this study, I will use a national database to assess relationships between place-based social determinants of health, patient's individual risk profiles, and risk of SMM. Analyses provide a bird-eye view of the role of structural determinants and maternal morbidity nationally.

Hypothesis: Individual-level biologic risk factors (i.e., maternal disease states and age) and regional social determinants of health (i.e., indexes of community resources,

economic security, and healthcare accessibility) will significantly predict the occurrence of SMM at delivery and throughout the postpartum period.

1.10.3 Chapter 3, Manuscript 2

This study then utilizes in-depth qualitative interviews with healthcare providers and emergency medical technicians to assess underlying mechanisms of SMM and PRM in Appalachia. Investigation is centered in an area with known intermediary determinants of SMM and PRM, (i.e., high rates of chronic illness, adverse health behaviors, and limited specialist resources in healthcare). Interviews allow for the evaluation of structural determinants alongside intermediary determinants, and the interplay between these factors.

The CSDH framework states interventions must take into consideration social mechanisms which systematically produce inequitable distribution of health determinants, and subsequently, health outcomes. Providers' and EMTs' perspectives are critical to elucidating these mechanisms. Providers and EMTs may assign distinct meanings to their encounters with SMM and PRM, and identify mechanisms concerning structural and intermediary determinants of SMM and PRM. The triangulation of these perspectives are central to a comprehensive understanding causes of SMM and PRM, and an in-depth evaluation of different stages of care.[54]

Anticipated Insights: Physicians and advanced practitioners will provide insight into the medical management of patients, and medical and social factors influencing poor outcomes among their patients. EMTs will provide insight into decision-making surrounding patient transport in an area where obstetric care is sparse.

1.10.4 Chapter 4, Manuscript 3

Similar to Chapter 3, this study then utilizes in-depth qualitative interviews with Appalachian women who have a personal history of SMM. These participants were questioned about their experiences with SMM, the determinants they believed contributed to their poor outcomes, and potential points of intervention. Parallel to the interviews conducted in Chapter 3, interviews provide patients with the opportunity to discuss causal mechanisms contributing to their SMM experiences.

Anticipated Insights: Patients will provide insight regarding their cultural values, how socioeconomic position affects interactions with healthcare providers, and barriers to healthcare utilization.

1.10.5 Chapter 5

This summary chapter concludes the dissertation. This chapter will focus on how proposed models for tailoring prenatal care based on individual patient need may benefit from greater consideration of structural determinants and the challenges faced by rural populations. This chapter also explores the role of the clinician in alleviating maternal health disparities, with particular emphasis placed on medical stewardship.

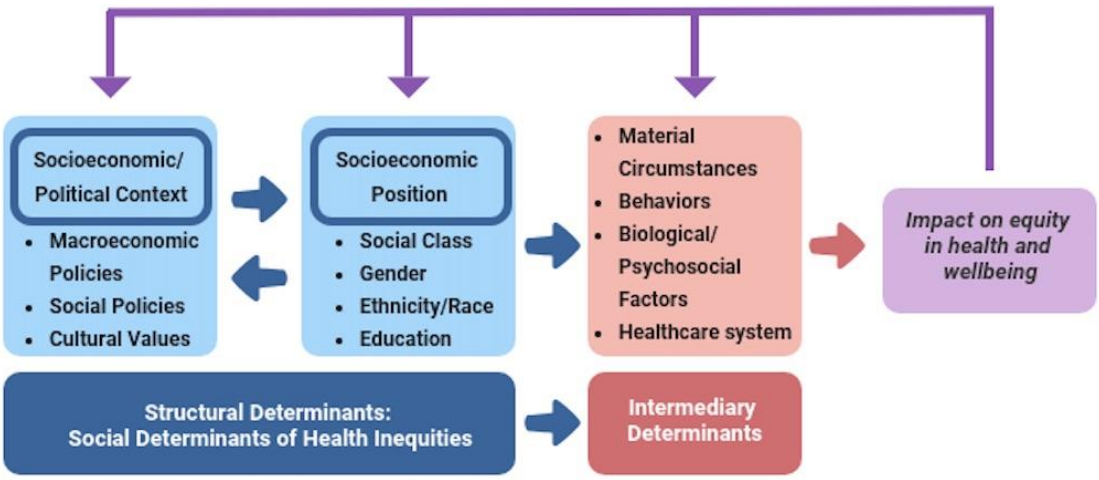

Figure 1.2. A simplified CSDH framework[48]

CHAPTER 2. MULTI-LEVEL MODELING OF INDIVIDUAL AND PLACE-BASED DETERMINANTS OF SEVERE MATERNAL MORBIDITY

2.1 Introduction

Severe maternal morbidity (SMM) is a growing public health problem in the United States (US). Cases of SMM have nearly tripled since the turn of the 21st century, and an estimated 50,000 US women experience SMM every year.[1, 2, 55] SMM is defined as unexpected outcomes of labor and delivery, resulting in significant short- or long-term consequences to a woman's health.[1] The Centers for Disease Control and Prevention (CDC) operationalizes SMM using 21 diagnostic and procedural indicators which capture a range of morbidity events.[56] Indicators include events such as blood product transfusions, ventilation, sepsis, and cardiac arrest.

Although rates of SMM are increasing across the US, not all populations of pregnant and puerperal women are equally affected. Past population level analyses have demonstrated an increased risk for SMM and pregnancy-related mortality (PRM) among women with common chronic illnesses including hypertension, pre-existing diabetes, substance use disorders, and chronic heart, respiratory, renal, and liver diseases.[8] Women of minoritized groups, including Black, Hispanic, and Native women, experience SMM and PRM at a disproportionate rate in the US.[29, 57, 58] Rural women, low-income women and women living in certain geographic regions similarly experience higher rates of SMM.[59, 60]

Underlying the epidemiological landscape of disease burden are place-based social determinants of health. Social determinants of health are the conditions in the environment in which individuals are born, live, and age that affect a wide range of health outcomes.[61]

Geographic location may determine a patient's access to vital resources, including quality healthcare, nutrition, economic security, and safe housing.[62] Such place-based factors may influence a woman's risk of experiencing an adverse health outcome, including SMM, both directly and indirectly.[62] Directly, place influences healthcare availability, environmental exposures, and proximity to epigenetic-altering chronic stressors. Indirectly, place influences a woman's ability to adopt advantageous health practices, such as optimal nutrition and physical activity. Employing hierarchical logistic regression modeling and nesting women within their geographic environments allows this study to evaluate the role of place on a woman's risk of SMM.[62]

The conceptual framework for action on the social determinants of health adopted by the World Health Organization's (WHO) Commission on the Social Determinants of Health (i.e. the CSDH framework) provides further theoretical support for the consideration of place-based determinants when examining disparities in SMM.[48] The CSDH framework posits that to alleviate disparate health outcomes, consideration of individual risk factors alone is insufficient. Structural factors, such as the social and economic contexts in which individuals live, are key to understanding and alleviating disparate health outcomes. Structural determinants, according to the CSDH framework, mold the differential vulnerability and differential consequences experienced by patients.[48] The place-based social determinants of health examined in this study, including broad measures of the economic security and resource availability of an area, capture structural determinants central to the CSDH framework.

Understanding the individual and place-based factors contributing to SMM events is essential to reducing maternal mortality in the US. SMM is strongly associated with

PRM.[5] Women who experience SMM at delivery are approximately 400 times as likely to die in the first year post-partum.[5] Although the increasing incidence of SMM and PRM in the US is well-documented, challenges arise when surveilling postpartum outcomes. Examination of emergency department and inpatient encounters during the first post-partum year is essential for understanding a woman's risk for poor outcomes that occur outside of the delivery hospitalization.

This study seeks to examine how place-based social determinants of health impact women's risk of SMM and PRM at delivery and throughout the first post-partum year. This study utilizes a national sample of women's delivery hospitalizations from 2016-2018 linked to inpatient and emergency department encounters throughout the first post-partum year. This study discusses how both individual-and contextual, place-based risk factors influence women's risk for SMM throughout delivery and the post-partum period.

2.2 Methods

2.2.1 Data Source

This paper conducts a retrospective analysis of a national sample of females aged 12-55. The sample includes all girls and women with documented delivery hospitalizations in the MarketScan Research Database between 2016 and 2017, and one-year of post-partum follow-up encounters from 2017-2018. These years reflect the most recent years of available data, as well as years utilizing the most recent International Classification of Disease coding (10th Revision, ICD-10).[63] MarketScan captures person-specific clinical utilization across inpatient and outpatient services. The data come from a selection of large employers and health plans. This database links paid claims and encounter data to detailed

patient information across sites, types of providers, and over time. Each year of data includes private-sector health data from approximately 350 payers, and encompasses over 20 billion records total. MarketScan include data on patients across the US and is nationally representative for covered populations. Documentation for each encounter includes ICD-10 diagnosis codes, Current Procedural Terminology (CPT) procedure codes, discharge status, length of stay, and demographic data including age and geographic indicators of patient residence.

Delivery hospitalizations within MarketScan were identified using ICD-10 inclusion and exclusion criteria defined by the Alliance for Innovation on Maternal Health.[64] ICD-10-Procedure Coding System (PCS) codes were translated to CPT codes with the help of a professional medical coder at the University of Kentucky. MarketScan was available to the research team through the University of Kentucky Center for Clinical and Translational Science. Use of this database for these analyses was approved by the institutional review board at the University of Kentucky.

2.2.2 Variables of Interest

2.2.2.1 Overview

This study controls for two levels of predictors: individual risk factors assigned to each patient, and place-based risk factors assigned to the metropolitan statistical area (MSA) of each patient's home residence at the time of delivery. These two levels of predictors allow individual patients to be nested within their MSAs.

2.2.2.2 Outcome

SMM events were identified using CDC ICD-10 criteria and CPT coding. SMM was measured dichotomously, with the presence of any SMM diagnostic or procedural

indicator constituting an SMM event. Discharge status, including death, was assessed through documentation in MarketScan.

2.2.2.3 Level 1: Individual Risk Factors

Existing research demonstrates an association between SMM and individual risk factors including maternal age at delivery and common chronic conditions.[8] Chronic diseases were identified using ICD-10 diagnosis codes.[65] These include dichotomous indicators for chronic hypertension, pre-existing diabetes mellitus, substance use disorders, and chronic respiratory, renal, liver and heart disease. Information on individual race and ethnicity is not available through MarketScan.

2.2.2.4 Level 2: Place-Based Risk Factors

Place-based determinants provide further information concerning the environment in which individuals live, and affect a wide range of health outcomes.[61] Women were nested within the metropolitan statistical area (MSA) of their home residence. The US Office of Management and Budget defines an MSA as a core area containing a population "nucleus" and its surrounding communities with a high degree of social and economic integration.[66] There are 393 MSAs across the United States.

I selected the Social Determinants of Health Index (SDOHi) because of its utility in comprehensively measuring place-based risk factors predictive of local health. The SDOHi is derived from place-based data elements from the American Community Survey, the US Department of Agriculture, the CDC, and other national data sources. The SDOHi is comprised of measures of healthcare access, food access, resources access, housing, transportation, and economic security, and provides a numerical value to each MSA.

Additional measures are available through component indexes of the SDOHi including economic security and resource accessibility, as well as three measures of healthcare accessibility (Table 2.1). Higher SDOHi and component measure scores indicate better-quality social conditions (i.e., higher economic security scores indicate community members are employed, insured, and otherwise financially stable). The SDOHi is merged with the MarketScan Research Database.

2.2.3 Statistical Analyses

Following the identification of SMM events, the rate of SMM per 1,000 patients was estimated. The distribution of demographic characteristics and chronic disease states among patients hospitalized for delivery was examined. Next, chi-square analyses were used to assess whether patient-level predictors were associated with SMM.

SDOHi scores and component SDOHi measures were assigned to each patient depending on the MSA of their home residence. All continuous MSA-level measures were grand-mean centered.

In addition, discharge status was examined to assess mortality within 1-year post-discharge from the delivery hospitalization. The linked nature of MarketScan data facilitated enhanced surveillance of patients throughout the first year post-partum.

Next, hierarchical logistic regression was used to model aforementioned predictors of SMM at delivery and throughout the first postpartum year. Women were clustered by the MSA of their home residence. Predictors were added in three consecutive models: (1) a null model, (2) a model with individual-level predictors and the SDOHi as an MSA-level predictor, and (3) a model with individual-level predictors and component measures of the

SDOHi as MSA-level predictors (Table 2). Assessing component measures of the SDOHi as distinct MSA-level predictors facilitated assessment of specific social determinants of health. Models were compared using a log likelihood ratio test.

Statistical significance was determined at an alpha level of 0.05. All analyses were conducted using Stata v.16.0. The final sample consisted of 281,495 women. Within the sample 228,514 had documented MSA data. All individuals were included in bivariate and descriptive analyses. Regression analyses were limited to women with documented MSA data. All available data for women with multiple delivery hospitalizations within the study period were included in analyses.

2.3 Results

2.3.1 Descriptive Analyses

Women's ages ranged from 13 to 55 at the time of delivery, with an average age of 30.3 years (SD=5.3 years). Table 2 describes the age of this sample and common disease states associated with poor maternal outcomes. There existed a significant bivariate relationship between SMM and age, chronic hypertension, pre-existing diabetes, and chronic respiratory, renal, liver and heart disease.

1,620 women (0.58%) experienced an SMM event. The most common severe maternal morbidities involved blood transfusion (N=1,291), eclampsia (N=352) and disseminated intravascular coagulation (DIC; N=361).

No discharge statuses were documented as deaths. However, a total of 18 patients were discharged to hospice services following hospitalization. Given the extremely small

subset of patients who received hospice care and lack of intra-hospitalization deaths, the remainder of analyses are limited to SMM.

2.3.2 Regression Analyses

In Table 3, I report odds-ratio results of hierarchical logistic regression analyses predicting an individual's risk of SMM throughout the first post-partum year.

2.3.2.1 Null Model

The null model yields a significant random intercept for MSA. The intraclass coefficient (ICC) establishes an estimated 1.1% of the chance of experiencing SMM at delivery or in the first postpartum year is explained by between-MSA differences captured by the data. The ICC demonstrates small yet statistically significant importance according to the MSA, and warrants further investigation into the effect of MSA-level predictors and how the effect of individual-level predictors varies between clusters.

2.3.2.2 Model 1

Model 1 reports odds-ratio results when controlling for maternal age and common chronic illnesses as level-1 predictors and composite SDOHi scores as level-2 predictors. Individuals of advanced maternal age experienced increased odds of SMM, with greatest odds incurred by women >40. Compared to women aged 26-35 years old, women aged 36-40 experienced 1.45 time the odds of SMM, and women >40 experienced 2.11 times the odds of SMM. Women with diagnoses of common chronic illnesses, including chronic hypertension, preexisting diabetes, substance use disorders, and chronic respiratory, renal, liver or heart disease also experienced increased odds of SMM. Chronic hypertension and chronic heart disease proved the strongest predictors; women with chronic hypertension

experienced 14.33 times the odds of SMM, while women with chronic heart disease experienced 10.79 times the odds of SMM. Importantly, the SDOHi did not significantly predict SMM, indicating the SDOHi as a single, comprehensive measure does not predict SMM in this sample. Further analyses evaluate the component metrics of the SDOHi. Variance around the intercept in Models 2 was not shown to be significant, demonstrating non-significant variation in the mean odds of SMM between MSAs when controlling for level-1 and level-2 predictors.

2.3.2.3 Model 2

Model 2 reports odds-ratio results when controlling for level-1 predictors and component measures from the SDOHi. Similar to Model 1, all level-1 predictors remained significant. The SDOHi measure of economic security was a significant predictor. A point increase from the mean in the economic security index predicted a 3% decrease in the odds of SMM. Measures of resource accessibility, physician density, obstetrician-gynecologist (OB/GYN) density, and pediatrician density were not significant predictors of SMM. Compared to Model 1, a log likelihood ratio test yields significant results (P=0.02). Similar to Model 1, variance around the intercept in Models 2 was not shown to be significant, demonstrating non-significant variation in the mean odds of SMM between MSAs when controlling for level-1 and level-2 predictors.

2.4 Discussion

2.4.1 The Maternal Risk Profile

Identifying predictors of SMM is crucial to framing evidence-based interventions. Results of this study provide further evidence that a patients' individual risk profile plays

a critical role in predicting their risk of SMM. In addition to individual-level predictors, results of this study highlight the importance of place-based social determinants of health. Risk factors for SMM extend beyond an individual's demographic profile and past medical history, and into the social environment. Investigation of place-based social determinants of health may illuminate points of intervention which target not an individual patient, but the social context in which a patient lives.

Consistent with past studies, advanced maternal age (>35 years) was significantly associated with increased odds of SMM.[11, 67] Within this sample, the greatest risk was incurred by women over 40. Also consistent with prior research is the risk attributable to individual diagnoses of chronic illnesses.[8] Past medical histories of chronic hypertension, preexisting diabetes, substance use disorders, and chronic respiratory, renal, liver or heart disease are associated with increased odds of SMM, with greatest risk incurred by chronic hypertension and chronic heart disease. The importance of these diseases as risk factors for SMM is especially salient considering cardiovascular conditions are responsible for an estimated one-third of pregnancy-related deaths.[68] Interventions targeting the management of chronic hypertension and cardiovascular disease in women of childbearing age are crucial for alleviating SMM and PRM, including comprehensive reproductive planning.[69]

The distribution of chronic illnesses among women of childbearing age reflect stark inequities. Chronic illnesses disproportionately impact low-income women, rural women, and Black American women of childbearing age.[55] Within this sample, economic security is inversely correlated with chronic heart disease, chronic hypertension, substance use disorders, and diabetes, further demonstrating maternal chronic illnesses are a product of underlying inequity.

2.4.2 Place-Based Risk Factors: Economic Insecurity and Maternal Health

The economic security of an MSA in which a patient lives also significantly predicted SMM, with a point increase from the mean in the economic security index predicted a 3% decrease in the odds of SMM. Economic security is as a component measure within the SDOHi, providing an index of employment rates, labor force participation, individuals with health insurance coverage, and household income above poverty level. Economic security scores varied broadly across MSAs, ranging from 31.1 to 62.8. Such variation indicates economic security may yield a substantial effect among patients in MSAs that fall far below the mean index score.

Past studies have called for greater investigation into the relationship between economic security and maternal mortality in "developed" countries, and specifically within the US.[70] Economic security may impact a patient's risk of SMM both directly and indirectly. Directly, living in an economically insecure setting may function as a chronic stressor. Self-reported stress levels and biologic stress markers have been associated with poor perinatal outcomes and delayed antenatal care. [22] Indirectly, economic insecurity may influence a woman's ability to adopt advantageous health practices, such as healthcare utilization and health-promoting behaviors. Poverty is associated with decreased use of healthcare services, potentially due to inability to afford services, lack of time or non-monetary resources (e.g. transportation to appointments), and discrimination within healthcare.[70] Women living in poverty are also more likely to experience food insufficiencies and hunger, predisposing them to malnutrition, and subsequently, anemia and infections during pregnancy.[70]

Elements of healthcare utilization, including the density of physicians and OB/GYN specialists, did not significantly predict SMM. However, increased density of physicians may facilitate diagnosis of SMM criteria for women with severe complications. This diagnostic benefit with physicians may counteract the expected increased risk for poor outcomes alongside poor healthcare access.

2.4.3 Incorporating Social Context into Mortality Prevention

Between half and two-thirds of PRM cases in the US are deemed preventable.[35-37] However, definitions of a preventable maternal death have persistently relied on concepts of clinical preventability, rather than social preventability. Evaluations of PRM cases have defined four categories of preventable deaths: (1) pre-conception care, in which patients should have received counseling concerning a severe risk for pregnancy complications given known preexisting medical conditions; (2) patient actions, in which patients did not adhere to medical advice, refused necessary treatment, or failed to seek care in a timely fashion; (3) system factors, in which the overall functioning of the health care system resulted in non-optimal care; and (4) quality of care, in which the care provided to the patient fell below the expected standards given the level of the facility.[18] Although these definitions are applied to PRM, they may be considered in evaluations of SMM, as SMM represents cases of near-miss mortality and incurs a 400 times higher risk of dying from pregnancy-related causes.[13]

These classifications of preventability focus on points of intervention within the clinical sphere. However, they do not account for the social conditions in which patients, providers, and healthcare systems function. Results from this study demonstrate the need for a reconceptualization of preventability that facilitates social interventions alongside

clinical interventions. Understanding the mechanism through which economic security impacts maternal outcomes may provide context for clinically preventable deaths. For instance, economic insecurity may directly contribute a patient's adherence to medical advice or ability to seek care in a timely fashion. Moreover, social conditions such as economic security may provide a novel lens through which to intervene. Social conditions may account for cases of mortality previously deemed unpreventable.

Economic policies may be modified to alleviate health disparities among women living in economically insecure areas. Social safety net programs have provided greater benefit to married couples, the older population, and lower middle-class families compared to single mothers and families living in more severe poverty.[71] The expansion of social safety-net programs focused on mothers and families living in more severe poverty and more economically disadvantaged areas may help promote maternal health and reduce the burden of maternal mortality.[71] In sum, the significant effect of regional economic insecurity and SMM warrants further study, and highlights a potential area of intervention for socially preventable cases of SMM.

2.5 Limitations

A significant limitation of the data source used in this study is the lack of information on patient race and ethnicity. Given the persistent and significant relationship between maternal race and risk of SMM, lack of information on race and ethnicity may disregard crucial insight into risk assessment and evaluating the role of social context.

The MarketScan Research Database does not provide information on Medicaid recipients. However, recent studies have indicated no difference in SMM risk between

patients with Medicaid compared to patients with private insurance. Despite minimal demonstrable differences in maternal pregnancy outcomes between Medicaid recipients and privately insured women, previous studies have used Medicaid as an indicator of low socioeconomic status and poverty. Rather than using Medicaid as a status of individual socioeconomic status, this study provides contextual information on the economic environment within which patients reside.

Women who live outside MSA boundaries were excluded from analyses. Consequently, women living in remote rural areas were not included in analyses. Rural women are at increased risk for SMM and PRM compared to urban counterparts. Future studies may assess the role of place-based social determinants of health on a more granular geographic level to include smaller populations of at-risk patients.

2.6 Conclusions

Despite these limitations, findings from this paper illuminate the significant influence of socioeconomic context on SMM morbidity, and highlights the role of place-based economic factors on maternal health. Furthermore, interventions addressing economic policy may enhance maternal health and alleviate disparities among women living in economically insecure regions.

Table 2.1 Definitions of SDOHi measures.

SDOHi Measures	Definition
Economic Security	Index measure of employment rates, labor force participation, individuals with health insurance coverage, and household income above poverty level. Range from 0-100, with higher numbers indicating higher levels of economic security.
Resource Accessibility	Index measure of community resources including quantity of libraries and religious institutions per 10,000 residents, employment rates for people over 65, and presence of a grocery store within 20 miles. Range from 0-100, with higher numbers indicating higher levels of resource accessibility.
Elements of Healthcare Accessibility	
Physician density	Active MD physicians per 1,000 residents
Density of OB/GYNs	Concentration of OB/GYNs per 1,000 residents
Density of pediatricians	Concentration of pediatricians per 1,000 residents

Table 2.2 Bivariate analysis between patient-level predictors and SMM.

Characteristic	**N(%)**	**Association with SMM**
Maternal age		P<0.001
<18	1,182 (0.42%)	
18-25	54,770 (19.46%)	
26-35	180,452 (64.10%)	
36-40	38,638 (13.73%)	
>40	6,453 (2.29%)	
Chronic hypertension	1,444 (0.51%)	P<0.001
Pre-existing diabetes	2,025 (0.72%)	P<0.001
Substance use disorder	914 (0.32%)	P=0.23
Chronic respiratory disease	8,589 (3.05%)	P=0.001
Chronic renal disease	167 (0.06%)	P<0.001
Chronic liver disease	394 (0.14%)	P<0.001
Chronic heart disease	1,157 (0.41%)	P<0.001

Table 2.3 Parameter estimates [a] (odds ratio) for SMM during first postpartum year.

Explanatory variables	Model 0 [b]	Model 1	Model 2
Fixed effects			
Intercept	-5.14	0.005 (0.0002)	0.005 (0.0002)
Maternal age			
<18 vs. 26-35		1.19 (0.54)	1.17 (0.53)
18-25 vs. 26-35		1.11 (0.09)	1.10 (0.08)
36-40 vs. 26-35		1.45*** (0.11)	1.46*** (0.11)
>40 vs. 26-35		2.11*** (0.27)	2.12*** (0.27)
Disease states			
Chronic hypertension		14.33*** (1.59)	14.13*** (1.57)
Pre-existing diabetes		2.04*** (0.40)	2.02*** (0.40)
Chronic respiratory disease		1.54** (0.20)	1.55** (0.20)
Chronic renal disease		5.08*** (1.61)	5.09*** (1.61)
Chronic liver disease		2.34* (0.97)	2.37* (0.98)
Chronic heart disease		10.79*** (1.45)	10.64*** (1.43)
Substance use disorder		2.16* (0.78)	2.14* (0.77)
SDOHi composite score		1.00 (0.008)	
SDOHi elements			
Economic Security			0.97*** (0.01)
Resource Accessibility			1.00 (0.02)
Elements of Healthcare Accessibility			
Physician density			0.94 (0.05)
Density of OB/GYNs			4.43 (6.59)
Density of pediatricians			1.58 (1.34)
Random effects			
MSA Intercept Variance	0.036	0.15 (0.06)	3.23e-10
Model Estimates			
AIC		15,221.85	15,218.19
N - Individuals	259,395	219,663	219,663
N - MSAs		391	391

[a] The parameters for fixed effects are reported as odds ratio (standard error); for random effect, the parameter is the variance

[b] Null model with no covariates

* $p \leq 0.05$

** $p \leq 0.01$

***$p \leq 0.001$

CHAPTER 3. STRUCTURAL AND INTERMEDIARY DETERMINANTS OF MATERNAL MORBIDITY AND MORTALITY IN A HIGH-RISK, RURAL PATIENT POPULATION: RESULTS OF A QUALITATIVE STUDY WITH OBSTETRIC PROVIDERS AND EMERGENCY MEDICAL TECHNICIANS

3.1 Introduction

Over the past two decades, women in the United States (US) have faced a steadily increasing risk of dying from pregnancy-related causes and experiencing severe morbidities attributable to pregnancy.[1] The number of American women suffering pregnancy-related mortality (PRM), defined as the death of a woman during or within one year of pregnancy due to pregnancy-related complications or aggravated preexisting conditions, has nearly doubled since the turn of the 21st century. Cases of severe maternal morbidity (SMM), defined as the occurrence of end-organ damage in the mother encompassing unexpected outcomes of labor and delivery, have nearly tripled.[1, 2] Patterns in the prevalence and etiology of SMM and PRM across the US reflect the consequences of patients' pre-pregnancy health, access to healthcare, and social determinants of health.[1] Women living in rural areas, women with common chronic illnesses, Black women, and Native American/Alaska Native women in the US are at increased risk for PRM.[1, 2, 8, 35, 59, 72] Such inequities compel researchers to elucidate determinants of SMM and PRM among health disparate populations. This study examines the unique perspective of providers who have cared for women with SMM and/or PRM within a high-risk and underserved population. Namely, this study employs qualitative methods to characterize Appalachian providers' experiences treating women with SMM and/or PRM, highlight perceived contributing factors to SMM and PRM, and identify points of intervention.

This study examines SMM and PRM in the context of Appalachia. Rural Appalachian women fit the NIH criteria for a health disparate population due to their underserved status and high disease burden,[73] and embody multiple known risk factors for poor maternal pregnancy outcomes.[74] Appalachia is home to nearly 25 million residents across 13 states.[7] Although the region is home to diverse subpopulations and local economies, Appalachia is characterized by rural geography and widespread economic distress.[7] Central Appalachia, encompassing areas of Kentucky, Tennessee, and West Virginia, is home to predominantly rural communities facing especially severe rates of unemployment and poverty.[33]

Appalachian women face a distinct risk profile for SMM and PRM,[74] and experience an increased odds of SMM at delivery.[11] Appalachian women of childbearing age are in poorer health prior to the conception of pregnancy, including worse self-reported health, and higher rates of smoking, obesity, and poor nutrition compared to their non-Appalachian counterparts.[7] However, high disease burden does not entirely account for disparate outcomes; Appalachian women face increased odds of SMM even when controlling for known patient-level risk factors, including chronic disease states.[11] These regional disparities warrant investigation of structural factors influencing poor maternal health.

Appalachian women have sparse resources with respect to risk detection and crisis management when complications arise. Availability of specialty physicians, including obstetricians and high risk maternal-fetal medicine specialists, is 65% lower in rural and economically distressed areas of Appalachia compared to the country as a whole.[34] Accessibility of obstetric care in Appalachia is worsening,[75] mirroring trends throughout

rural communities nationally; >80% of rural counties lack a hospital with obstetric services.[21, 76] Closures shift obstetric management from the hospital setting to local clinic staff and emergency medical technicians (EMTs), who may not be equally equipped to provide obstetric care.[21]

Obstetric care providers and EMTs who have treated and managed women who experienced SMM or died from pregnancy-related causes maintain a unique perspective on underlying causes of poor maternal pregnancy outcomes and points of future intervention. Providers are uniquely able to speak to challenges surrounding patient management and healthcare resources within their practices. Additionally, providers may voice insight into prevalent patterns within their patient populations, such as barriers surrounding healthcare utilization[77] and causal mechanisms underlying health inequities in Appalachian communities.[78]

The objective of this study was to elucidate obstetric care providers and EMTs experiences caring for women with SMM and/or PRM, characterize perceived contributing factors, and identify points of future intervention through in-depth, qualitative interviews. Interviews were similarly conducted with Appalachian women with histories of SMM; these findings are reported elsewhere (see Chapter 4). By utilizing the conceptual framework for action on the social determinants of health adopted by the World Health Organization (WHO), this paper examines distinct levels and mechanisms of causation resulting in disparities in SMM and PRM in an at-risk population.[47, 48]

3.1.1 Theoretical Framework

This study utilizes the conceptual framework for action on the social determinants of health adopted by the WHO Commission on the Social Determinants of Health (i.e., the CSDH framework) to inform qualitative interview questions and data analysis. The CSDH framework synthesizes different frameworks of the social determinants of health to create a comprehensive conceptual tool that may be used to guide empirical work, enhance understandings of determinants underlying poor health, and identify points of intervention.

Creators of the CSDH framework posit the social gradient of health is caused by the unequal distribution of power, income, and services, leading to downstream inequities in individuals' immediate living conditions. The CSDH framework comprises two broad categories of determinants: *intermediate* and *structural*. Intermediate determinants encompass individuals' places within social hierarchies based on their social status, relative exposure to health-compromising conditions, and ability to utilize health-promoting tools. Intermediate determinants include material resources available to an individual, biologic and psychosocial risk factors, and factors related to local healthcare systems. Structural determinants generate social stratification, and determine an individuals' position within a social hierarchy. Structural determinants comprise socioeconomic position with respect to class, education, race, and gender. Additionally, structural determinants include the key social, economic, and political contexts that define socioeconomic position. The CSDH framework employs a broad definition of *context* to include all social, economic, and political mechanisms that generate and maintain social hierarchies.

The CSDH framework acknowledges a feedback loop between illness and upstream determinants. An illness may impact an individual's intermediate determinants (e.g.,

material circumstances, health behaviors) and socioeconomic position (e.g., employment status, income). Prevalent illnesses within populations may also impact cultural values as well as social, economic, and political policies.

In sum, the CSDH framework encourages researchers to study both the material limitations of individuals' lives, as well as the social policies, inequitable economic arrangements, and political policies that influence the distribution of health-damaging experiences. By identifying social contexts, differential vulnerability, and differential consequences experienced by patients, the CSDH framework highlights distinct levels and mechanisms of causation resulting in health inequity.[47, 48] By framing health as an outcome of social phenomena, the CSDH framework may be used as a tool to promote health equity, and recognize health disparities as social injustices.

The CSDH framework has been used to synthesize current literature on the social determinants of maternal mortality in the US, and identify potential areas of clinical and public health intervention.[49] There exists a scarcity in studies examining the role of socioeconomic and political context and poor maternal outcomes. The relationship between these structural constructs and disparate rates of SMM and PRM is identified as a crucial gap in current literature. [49] Additionally, few studies have explored causal pathways between social determinants and maternal health disparities, and how structural and intermediate determinants influence one another to impact disparate health outcomes.[49] Lastly, minimal attention has been paid to regional differences in maternal health outcomes within the US.[49]

This study seeks to address these current gaps in the literature. Specifically, this study utilizes the CSDH framework to examine understudied structural constructs and the

interplay between structural and intermediary determinants. Additionally, this study focuses on an understudied and underserved patient population within a distinct region.

3.2 Methods

3.2.1 Research Design

Semi-structured in-depth qualitative interviews were conducted with obstetric care providers and EMTs. Interview questions were informed by the CSDH framework. Questions pertained to intermediary and structural determinants of SMM and potential points of intervention.

3.2.2 Setting and Participants

A total of twenty Appalachian individuals participated; ten EMTs who had provided emergency care for women with severe pregnancy complications, and ten obstetric care providers practicing in Appalachia. Obstetric care providers and EMTs were recruited via snowball sampling, and were eligible if they practiced professionally in an Appalachian county and provided care for a woman with SMM. Snowball sampling involved sending emails through physician and EMT professional contacts known to the PI (AH) to recruit seeds, and posting fliers in obstetric care clinics. All participants were at least 18 years of age.

3.2.3 Data Collection

All interviews were conducted by the study PI (AH). In light of the COVID-19 pandemic, all interviews were conducted remotely. Participants decided on a medium of communication (i.e., phone or Zoom) and time for the interview. Interviews lasted approximately one hour. Participants were asked about their experiences providing care for

women who experienced SMM or died from pregnancy-related causes. Additionally, they were questioned about their perceptions of factors contributing to SMM and PRM, including both intermediate determinants (e.g., healthcare system factors) and structural determinants (e.g., cultural values). Lastly, participants were asked questions about potential strategies for future interventions to alleviate SMM and PRM among their patient population. EMTs were provided with a fifty-dollar check for their participation. Obstetric care providers were entered into a raffle to win a signed photograph of Kentucky basketball coach John Calipari, donated to the research team by University of Kentucky athletics.

3.2.4 Data Analysis

Interviews were recorded with participants' consent and transcribed verbatim by the PI. NVivo software facilitated qualitative analysis. Transcripts were analyzed using inductive coding, a strategy which identifies patterned responses directly from the data.[79] To enhance rigor, two coders independently reviewed interview transcripts, proposed an initial codebook, and established an initial coding protocol. Memos within NVivo software documented the identification of new themes and enhanced data interpretation. The coders established an inter-rater reliability of $K \geq 0.8$ for provider and EMT interviews. Analysis continued until team members reached thematic saturation (i.e. incoming data produced little new information to address the research question).[80] Following content analysis, the authors organized themes according to the CSDH framework (i.e. intermediary and structural determinants).

3.2.5 Ethics and Permission

Verbal consent was obtained from each participant before the initiation of the interview. The consent process involved a cover letter explaining the aims of the study, descriptions of the interview process, possible risks of participation, and information concerning the study's funding. Each participant was emailed the cover letter. Prior to the interview, the PI reviewed the cover letter with the participant and addressed questions. Consent was obtained once the cover letter was thoroughly reviewed and the participant affirmed (i.e., a vocalized "yes") that their continued participation indicated consent. Ethical approval was granted by the University of Kentucky institutional review board.

3.3 Findings

Below, findings are organized as follows: participant demographics, intermediary determinants, and structural determinants. Key intermediary determinants included material circumstances (including basic needs, patient transportation, and food deserts), maternal substance use disorder (SUD), emergency transport, and pre-pregnancy health. Structural determinants involved socioeconomic position (including class and education), as well as socioeconomic and political contexts (including social and economic environments, and discrimination).

3.3.1 Participant demographics

Of the ten providers, nine were physicians and one was an advanced practice registered nurse. Of the physicians, eight had completed residencies in obstetrics and gynecology, and one had completed a residency in family medicine with an additional obstetric fellowship. Seven participants were female, and three were male. The mean age

was 41 years (SD=10). Providers reported a mean of 11 years in practice (SD=12), although responses ranged widely from 2 years to 40 years. Nine identified as non-Hispanic white, and one identified as "Asian American." All participants are referred to as "providers" to maintain confidentiality.

Of the ten EMTs, two were female and eight were male. The mean age was 38 years (SD=7). EMTs reported a mean of 14 years in practice (SD=7). All identified as non-Hispanic white.

3.3.2 Intermediary determinants

3.3.2.1 Material Circumstances.

BASIC NEEDS. Providers and EMTs explained how patients' limited material necessities restrained their abilities to adopt health-promoting behaviors and access timely obstetric care. EMTs and providers commented on struggles surrounding the attainment of basic needs among some high-risk patients. Provider 8 described:

> We have several patients that we're concerned, either about their financial means to take care of the infant upon discharge, or their social situation, transportation. Do they have food? Do they have clothing? I mean, I paid a lady's water bill this week in my office because I just started asking questions, because I could tell that there was something.

EMT 1 similarly noted:

> I think the biggest thing is, you know, communities around here are very poor. So, it's not feasible for a woman to drive to have a checkup every single week during her pregnancy.

Participants identified multiple points of intervention to better ensure patients' basic needs were met. Namely, they endorsed the need to expand affordable phone and internet services in rural Appalachian communities (Table 3.1).

TRANSPORTATION. Additional participants also noted long travel times to clinic appointments as a barrier to care utilization. Provider 8 explained,

> It complicates it, as far as our patient population, from a lack of transportation standpoint. Yeah, in being able to, let's say, go up there for their preoperative visit, then go up there for prenatal visit, then go there for delivery. Having the resources to be able to stay that far away from home is also very difficult for them.

EMT 2 similarly noted severe challenges surrounding transportation; "Some of them didn't have rides. The really impoverished people didn't have means to go, or a way to get there. So, they just didn't do it." EMT 1 echoed, "And it's not like she can just drive across town. She's having to drive 50 miles. So, it's a lot. And usually they have other kids, and it's just hard for them to keep that up."

FOOD DESERTS. When asked why Appalachian and rural women specifically experience excessive rates of blood transfusion, providers often noted the role of nutritional anemias. "I feel like iron deficiency anemia is rampant in this area," Provider 10 noted. Provider 1 explained, "I find that a lot of women are anemic to begin with, and I think that's because their diets are not good. They don't eat a lot of food rich in iron and proteins – things that would help them to make blood to begin with." Another explained her patients' nutritional status as malnourished; "It's fast food, but it's still malnutrition if you think about it. It's not actually getting correct iron and vitamins. So, we do have a pretty decent rate of anemia."

Providers frequently described poor nutritional intake as a product of a limited food landscape. One participant who grew up in the county in which she now practiced explained:

> And then being from Appalachia, rural area, obviously growing up here – the resources to be able to eat the diet that we're telling them that they need to eat is often unobtainable. So, we hear that a lot. Even though that's their desire, to do better, they financially cannot afford those foods that we're telling them to eat instead.

Concerning future interventions, participants stressed the need for greater availability and affordability of nutritious foods to manage and prevent maternal disease states. In particular, participants discussed the role of nutritious diets in preventing diabetes, hypertension, and nutritional anemias.

3.3.2.2 Substance Use Disorder in Pregnancy

When questioned about contributing factors to SMM and PRM, EMTs noted the toll of substance use disorders (SUDs) on maternal pregnancy outcomes. In particular, EMTs commented on the frequency of SUD among their pregnant patients with severe morbidities. EMT 6 sighed before explaining:

> I can't emphasize enough - I guess because I get so sick of seeing it - is the effect that drugs are having on our young people, especially these young mothers…You know, especially in rural areas, the effect is just so, so, so great. You just don't know how many people I have been to that…we was just too late to get to them. It's just over and over and over again. It's just totally unacceptable what's going on right now.

EMT 8 noted associations between SUD and interpersonal violence, a leading cause of pregnancy-related mortality:[81]

> I would say, especially on our end, because it seems like a lot of the ones that we will end up dealing with, and especially the ones that have the horrible, tragic outcomes, are drug related. And then, at least in our area, and then working through law enforcement, that kind of stuff, we've had a lot kind of circle around the human trafficking aspect, and the drugs is the tool to basically control a person…Then you add in the increased domestic violence…some of which can be very tragic outcomes, that kind of stuff, if there's an assault involved.

Providers similarly acknowledged the burden of SUD, particularly opioid use disorder (OUD), among their patient populations. Although providers largely endorsed support systems for women with SUD during pregnancy, resources for post-partum women were noted to be largely lacking. "Once the baby is delivered, [there's] not necessarily great continuity, not great continuation of care," Provider 2 explained. "So unfortunately, a lot of them run into issues with custody battles, and basic social service battles, and all of the stress of those situations end up letting them just relapse and kind of go back to their old lifestyles." Participants identified expanded follow-up and treatment options for postpartum women as a potential point of intervention (Table 3.1).

Providers often distinguished between patients receiving medication for addiction treatment (MAT) for OUD and those not receiving MAT. When speaking of widespread problems with opioids within the community, Provider 6 explained:

> I think that [high rates of opioid use disorder] is the unique part of the culture here. And because of that, you have these women who, you know, have marginal compliance, they have terrible veins, they have very poor social circumstance. You know, the ones [who] are not in the [MAT] programs… everything that goes along with that truly complicates prenatal care to a whole new level. And I think that's the unique thing about being in this part of the state.

Some providers noted the stigma around SUD in pregnancy may deter patients from presenting for prenatal care. "Unfortunately, with the drug epidemic becoming

generational in this area, we have a lot of patients who are scared, mistrustful and simply afraid to talk, or even to show for care," Provider 10 explained. However, providers frequently noted the benefit of MAT on maternal outcomes, especially through facilitating prenatal care adherence. Provider 8 explained that non-obstetric MAT providers often dismissed patients from their care once becoming pregnant:

> So, a lot of people that are already in programs in our county, right, let's say they're already in a Suboxone program somewhere else. That provider will immediately stop seeing them when they become pregnant, even though we're giving them the exact same medications. So, in some ways that works to our benefit, some ways it's kind of a disservice to them if they've been going there forever and they're well established. But by doing that, they are forced to seek obstetric care almost immediately.

Provider 2 echoed:

> So, we do have a lot of patients who have, for example, opiate dependence. That's one, which oddly enough, leads to better prenatal care because they come more frequently to get their medication assisted treatment. So, I would say that's kind of one advantage to their prenatal care. Because they do need their Suboxone, something just to help keep them through the pregnancy, and generally they're more compliant just because their maternal instinct is much stronger than their addictions.

Some providers noted prescribing policies in hindering the accessibility of MAT and licenses as an "extra hoop to jump through." As Provider 3 explained, "I do think some of the policies, when it comes to prescribing opioid maintenance therapy, makes it challenging for providers, which then trickled down to the patients and their ability to get it readily." Many providers identified expanded access of MAT for pregnant women as a critical point of intervention (Table 3.1).

Overall, providers strongly endorsed programs which integrated prenatal care alongside MAT; “We try to make everything coincide. Their Suboxone visit, the prenatal visit, etc.” Provider 8 explained. Greater incorporation of treatment services with prenatal visits were seen as an additional point of intervention (Table 3.1). Other participants noted the benefit of residential programs for women in MAT during pregnancy. Only one provider questioned the efficacy of MAT in her practice:

> So, I've been here long enough to see different programs roll through to try to help with opiate addiction. So, methadone clinics were established in the area, and then Suboxone clinics were established in the area…As far as the outcomes, in my personal opinion, data I’ve seen for mother and baby, I’m not sure that I have seen a huge improvement or a decrease in the mortality and morbidity with my patients that are currently substance abusers by these programs. I know other providers are probably going to feel different, but they continue to not only use their medical assisted treatment they’re provided, but they're still having their relapses and they're still using other illegal substances with this medication as well.

3.3.2.3 Emergency Transport.

Providers and EMTs strongly described the critical role of EMS in the management of pregnant and post-partum women in need of urgent medical intervention in rural Appalachia. Both providers and EMTs acknowledged difficulties surrounding the transport of patients to the “appropriate level of care” in settings with few obstetricians and no high-risk maternal-fetal medicine specialists readily available. Some providers voiced frustration that pregnant patients were transported to facilities without the capacity to provide sufficient care. When asked about protocols surrounding the transfer of pregnant women in need of urgent care, Provider 1 explained:

> Oh, there's nothing, it’s terrible. Like EMS will pick up women from their house, and they'll be like, ‘I think I’m in labor.’ And they take them to the nearest hospital…And I’m like, ‘Dude, those people don't have an obstetrician...I know it's

> a little bit farther ride, but you got to bring them to a hospital that actually has OB care.' I feel like they should at least triage it the way they do a stroke. Like if EMS has a patient who seems to be having a stroke, you're not supposed to take them to a hospital without a working CT scanner, because that's step one in stroke protocol, to do a CT scan of the head. So, if the CT scanner is down, you bypass that hospital and go immediately to the next one. And I feel like that should be there, should be some sort of guidelines like that for obstetrics. If they come with [an] obstetrical complaint, and the next nearest hospital does not have an OB/GYN, you bypass it and go to the next hospital.

Provider 5 noted the difficulty in transporting patients to facilities with appropriate care has been further complicated by closures of rural obstetric units. "It's not that unusual for me to get transfers from a couple of the other regional hospitals that are 30-45 minutes away in some cases, but just don't practice obstetrics anymore. At this point, we're down to one per county, sometimes less in this area," he explained.

EMTs provided critical insight into the challenges surrounding patient transport observed by providers. EMTs similarly conveyed frustration in the lack of obstetric resources available at nearby hospitals when transporting pregnant and post-partum patients with severe complications. They largely expressed awareness of the availability of obstetric resources throughout their region (i.e., where the nearest hospital with an OB provider was located). Most EMTs attributed this awareness to extensive on-the-job experience rather than formal curriculum during their initial training.

Despite the known lack of obstetric care resources at certain facilities, EMTs acknowledged additional constraints that often made transporting patients to the nearest hospital the only viable option, regardless of obstetric care availability. EMTs expressed that local EMS resources were largely limited to a handful of ambulances and EMS personnel. Transporting a patient far distances for high-risk obstetric care may come at the

expense of depleting resources for the rest of the population. “It’s like it looks now, because you can’t take an ambulance away from 10,000 people,” EMT 2 explained. He went on to say:

> No, it’s absolutely not the best method. Not the best method for the baby. It’s the best method for the ambulance service, because if we took everybody to Lexington [the nearest city with tertiary medical care], that’s three-and-a-half hours round-trip. If the county’s just got one ambulance, then yeah, that’s not gonna work. If we can take them to the hospital and they get ‘em stabilized, we can call somebody in to make that trip, and it doesn’t deplete resources.

EMTs noted specific policies within EMS that further complicated patient management in rural settings. For instance, one EMT noted frustration over limitations in medication administration during emergency transports. He noted tocolytic Magnesium administration, a medication used to inhibit uterine contraction and prevent convulsions in patients with eclampsia, required two providers certified in advanced life support (ALS; i.e., two paramedics). He explained, “There’s not an ambulance service I know of that runs a double paramedic right now. So, you couldn’t even give that, and that’s a state law. So, we’re kind of hamstrung, really.” Another voiced, “But we don’t have the resources, and rural Kentucky sure doesn’t have the resources. And it’s just kind of the way it is.”

Participants identified multiple strategies to enhance emergent transport (Table 3.1). Namely, strategies largely focused on preparing EMTs for critical yet rare obstetric emergencies. Participants proposed collaborations between EMT leadership and obstetric care providers to develop more extensive protocols for EMTs responding to obstetric emergencies, and posited a roundtable discussion with obstetric care stakeholders to identify standards of care for high-risk patients. Opportunities for continued clinical training in obstetric emergencies, such as annual simulation training, were also identified

as important strategies of intervention. Participants also reported the need for state EMS policies to be critically reevaluated to better serve rural EMS. EMTs noted some policies, such as limitations surrounding medication administration, were created with metropolitan communities in mind.

3.3.2.4 Biological Risk Factors and Poor Pre-Pregnancy Health

When questioned about factors underlying their patients' risk for SMM and PRM, providers frequently noted the high burden of chronic disease within their patient population and poor health during the prenatal period. "I think that patients often have complicated deliveries because they have complicated pregnancies," Provider 3 noted. She went on to explain, "The risk factors for postpartum hemorrhage are things like gestational diabetes or macrosomic infant. Or abruption, which can be drug-related or hypertension-related. So, I think, again, those chronic health issues come into play at time of delivery."

Another provider noted chronic diseases often precede pregnancy, but are first detected and diagnosed during prenatal care:

> So, there is a lot of diabetes. It's probably pre-existing, it's getting diagnosed at the time of their first prenatal visit. Or hypertension getting diagnosed at the time of their first prenatal visit, and sometimes even some heart problems that are getting diagnosed…There are a lot of health issues in this part of the state.

Providers rarely noted the prevalence of chronic disease without also noting the social conditions contributing to the epidemiologic landscape. Specifically, providers frequently noted the role of material circumstances (i.e., limited optimal food intake) and inadequate patient education as contributing to high rates of diabetes and hypertension.

3.3.3 Structural Determinants: Socioeconomic Position

3.3.3.1 Social Setting

Both EMTs and providers discussed how a patients' social and economic position influenced her interactions with the healthcare system. Some EMTs attributed patients' utilization of healthcare to their social upbringings and level of support. When asked what factors he believed influenced his patients' utilization of care, EMT 4 explained:

> I think it varies on the mother herself. Whether or not, if she's interested in taking care of herself, and she's interested in taking care of her of her unborn child. That's going to be the determining factor. What kind of home that she grew up in. If it was a loving, nurturing environment, or has she been on her own since she was basically 14?

Providers also noted how a patient's socioeconomic position may influence their clinical decision-making in cases where patients may struggle to receive follow-up care or lack significant support at home. Although providers noted the importance of following clinical guidelines (i.e., transfusing a patient according to trimester-specific hemoglobin levels), they also noted social factors may influence their decision to administer more aggressive care. Specifically, some providers reported accounting for patients' level of social support at home, their likelihood to present to follow-up care, and their distance from the hospital if a severe complication were to arise. Provider 5 explained,

> We're keeping the patient just typically one to two days [after delivery], and so sending somebody out with a hemoglobin of seven might be fine for somebody who has access to healthcare in the city. But I am more likely to transfuse somebody with that kind of hemoglobin, because my concern is not only about the mother's wellbeing, but also baby's wellbeing. If mom can't get up and take care of the family and the children, she is really hobbled. A lot of times these are single women and may, and probably don't, have much support. It really is about 'Do you want to risk somebody passing out at home with a baby in their arms?'

Provider 8 similarly noted:

> If I know that that person has the ability to, let's say, monitor their blood pressure at home, or I know that they are going to come back to me and be like, 'Hey, this was elevated, I'm having a headache.' Or if I think that that person has no ability to do that, and is not going to return to me, or I have concerns about their home environment, etc., I would keep them longer in the hospital to monitor and make sure that they have everything before they go home. So definitely the social factor is important.

3.3.3.2 Class

Providers often noted the role of class in patients' interactions with healthcare beyond barriers to material circumstances. Participants discussed class with respect to patients' financial realities. Some providers noted stigma towards patients living in severe poverty, and viewed this stigma as a barrier to care utilization. Provider 10 expressed:

> I think any of our patients who are in a tough situation, who are really struggling with financial crisis, really struggling with being on that edge of a stable home versus not, I think they really are afraid of what people are going to think when they walked through the door. I definitely had patients who…I mean, having a reliable shower can be a question at a time. And I know they are afraid that people would think they're just dirty or they don't try, when it's really, they don't have the opportunity to even do so.

EMTs provided a variety of perspectives when discussing class within their communities. Some EMTs noted the receipt of government benefits as a critical social stratifier, rather than as a means to alleviate inequities. EMT 1 explained,

> I feel like I am from a different class, I guess you would say, in this area. Because a lot of times, you have a couple of different classes. You have your working class and, you know, your people who work every day. You know, they don't receive government benefits, and they don't have things like that. And then you have your people who have never worked a day in their life, they're, you know, dependent on food stamps and Medicaid and things like that.

EMT 1, and other participants who noted government assistance programs as a means of social stratification, assigned a negative connotation toward the recipients of social welfare. “It's almost like everything has been given to them their entire lives, so they expect that…Like their expectations are unbelievable,” EMT 1 explained. Although such views were not universal among participants, EMTs who held this perspective on government assistance often described patients as passive players in their own obstetric care.

3.3.3.3 Education

Providers and EMTs both noted the role of education in patients’ healthcare utilization. Participants pointed to prenatal education as well as pre-conception education (e.g., the public school curriculum) as contributing to poor health literacy. Provider 3 explained,

> When you're starting out with somebody who literally doesn't know their own anatomy, you're starting from absolute scratch with all of those encounters. And so people, providers tend to not want to do that, and they don't have time to do it because there are so many patients. And so, they leave, and they still don't understand. Even after they've been in your office, they still don’t understand what's going on. I think that that's a huge issue. And providers not knowing how, not realizing that patients are starting from that level.

Providers directly attributed poor prenatal education as a risk factor for delayed healthcare utilization. “A lot of times I think they don't understand – even when we do education – I don't know that that these women always necessarily understand those risk signs to look for,” Provider 7 explained. “Sometimes we see patients…in the postpartum period, they've been given education before they leave the hospital, and then sometimes

we see them, and complications have kind of been brewing, and they haven't necessarily sought care in a timely fashion."

Many participants identified strategies for intervention related to education (Table 3.1). Participants suggested collaborations with local school systems and county health departments to introduce comprehensive health curriculum for teens and young adults. Additionally, participants integrated prenatal education during prenatal appointments (i.e., opportunities to meet with a prenatal educator during a prenatal appointment while waiting to be seen by the obstetric provider), as well as integrated consultations with dieticians during prenatal appointments.

3.3.4 Structural Determinants: Socioeconomic and Political Context

3.3.4.1 Economic and Social Policies

Participants expressed a connection between dramatic changes in the socioeconomic landscapes of their communities and more proximal determinants of maternal health. When asked to explain their associations with local culture, participants spoke extensively of regional job loss due to the decline of the coal industry and viability of farming. Participants elaborated on the widespread ramifications these economic shifts had on community wellbeing, intergenerational health, and pregnancy outcomes. EMT 5 explained:

> …We've also lost a generation now that did work in the fields through pregnancy. So, there's no one to turn to that they can look up to and say, 'well, they did it.' So, I think, almost the death of the old rural culture and the incipience of this new technical age is just…the job opportunities that are available just don't meet the needs of someone who is pregnant and a young woman.

In particular, participants connected maternal SUD to a decline in economic opportunity. EMT 6 expressed, “Something else you’ve got going on in Eastern Kentucky counties and stuff like that is the further you go east, towards Lee County, you start going up in Owsley County and those places like that, the drug use is just so…people don’t realize, it’s so astronomically high.” After discussing a specific case of maternal morbidity and fetal demise complicated by substance use, EMT 6 went on to explain:

> People in these counties – and I’m not using this as an excuse – but a lot of people in these counties, there’s nothing there. I mean Lee County, Kentucky – Beattyville, Lee County Kentucky – last year, year before last, was voted the second poorest county in all the United States. You have people there that’s basically, it’s sad to say, that don’t have anything to look forward to. They don’t have anything….They don’t have any hopes for the future.

Additionally, many participants spoke of government assistance programs when describing diminished economic opportunity within the region. Participants viewed social welfare programs complexly. Some viewed assistance programs as symptoms of a fraught economic landscape with diminished job opportunities. Other viewed them as part of an intergenerational “cycle” that perpetuated limited prospects for mothers and their children. EMT 5 explained:

> So, in turn, they either have to go to work or get government benefits. And a lot of times it’s easier to get the government benefits than it is to find a job, because they didn’t finish high school. And it’s…it’s a never-ending cycle. And it only seems to be getting worse in this area.

Provider 1 articulated:

> But right now, they're just in such a vicious circle of just getting a check, and you don't finish your education, so therefore you don't get a good job. And therefore, you start getting a government check again, and it just keeps [going] in a vicious cycle. And so, you're seeing a lot of these women, that's all they know. They're like,

> ‘Yeah, I make it to high school, then I get pregnant, and then I raise my kids by myself, without a really significant partner. My mom helps me and then, when my kids get to be teenagers, they’ll have their own babies, and that’s that. And that seems to just be the norm. So that's where you get the negative connotations about Appalachian culture, you know, about them being lazy or uneducated and obese. But I think it has a lot of deeper roots, you know. And I don't know how to break that cycle, but we have to do something...

Participants identified several points of intervention to alleviate challenges surrounding the social and economic contexts of their communities (Table 3.1). Although participants had diverse views on public assistance programs, providers discussed the value of expanding Medicaid coverage to 1-year postpartum to facilitate extended follow-up.

Several participants strongly endorsed expansion of Community Paramedics programs, which fund regular home visitation for at-risk patients. Participants explained Community Paramedics programs have been piloted in several rural Appalachian counties in Kentucky for older adults with chronic illnesses. Currently, such programs have not been applied to pregnant and post-partum populations. In order to successfully implement and expand such programs, participants spoke about the need to reevaluate EMS payment systems to allow compensation for home visits.

3.3.4.2 Discrimination

When asked of their associations with the term “discrimination” and how discrimination may impact healthcare, participants largely spoke of potential discrimination against low-income women, women with SUD, teen mothers, and “frequent fliers” who repeatedly utilize EMS and the emergency department. EMT 5 reported patients’ concerns may not be taken seriously by all providers, explaining:

> A woman who's pregnant who says, 'oh, I have belly pain,' and in your head, you're like, 'Oh, it's probably Braxton-Hicks' or 'it's probably this, it's probably that.' But if you don't have the experience, or you don't have the professionality to say, 'this is my patient, I need to treat them the way they present,' then it's really easy for you to say, 'yeah, this is a BS call, and I'm not gonna…we'll take you to the hospital, but that's it.' All it takes is one time for that to happen…

Similar sentiments were echoed by Provider 7, who explained:

> "I think a lot of these women definitely have experienced discrimination in healthcare. I think in general less educated women or women that come from kind of disadvantaged socioeconomic backgrounds, I think a lot of times they're dismissed, you know. Or even they may not be able to get across something that may be important for them to convey to their provider. They may not necessarily say it in the right way, or not know how to explain something that's going on. And so, I do, especially, you know, a lot of these women utilize the ER system a lot and I do think a lot of times they get dismissed there. And so, I think sometimes there can be a little bit of, may have this preconceived notion that, you know, their care isn't going to be as good because they've experienced this in the past.

Provider 4 alluded to the historical distrust of medicine. They described discrimination in healthcare as "an ingrained, multigenerational way of life."

Despite the stark inequities in SMM and PRM surrounding minoritized racial groups in the US, participants rarely noted the influence of race on poor pregnancy outcomes. Some participants immediately associated race with discrimination, but none noted racial disparities in their patient populations. These findings may be due to the lack of racial diversity in these predominantly white Appalachian counties.[33]

3.4 Discussion

Most participants viewed patients' SMM not as isolated events, but rather as symptomatic of underlying social and economic challenges facing their communities. Consistent with the CSDH framework, participants often endorsed a multidirectional

relationship between determinants of SMM and PRM. For instance, participants discussed how socioeconomic contexts (e.g. limited employment opportunities) influenced socioeconomic position (e.g. class, education) and intermediary determinants (e.g. prevalence of SUD, material circumstances). Intermediary determinants subsequently impact structural determinants (e.g. cultural values). Intermediary and structural determinants combine and culminate in poor maternal pregnancy outcomes.

The CSDH framework provides a platform to understand the consequences of regional economic hardship. The CSDH framework posits structural factors, such as the economic landscape of a region, impact individuals' immediate living conditions, and consequentially, the social gradient of health. Providers and EMTs spoke extensively of dramatically diminished opportunities for community development, and ramifications these economic and social shifts had on community health. The effects of regional economic distress are not unique to pregnancy; counties in Appalachia with high rates poverty exhibit increased all-cause mortality.[82] Focusing on maternal health allowed participants to explore how widespread poverty and limited economic opportunities impact women of childbearing age, and how disparate health outcomes are perpetuated intergenerationally. By discussing a "never-ending" and "vicious" cycle of poverty, participants expressed how their patients' pregnancy outcomes are influenced by their social and economic environments. These environments may also ultimately affect their patients' infants and the next generation of Appalachian adults.

Participants discussed mechanisms through which patients' social and economic environments heightened their risk for poor outcomes. Participants discussed patients' limited opportunities to adopt health-promoting behaviors prior to pregnancy due to

economic and educational constraints, specifically noting constraints surrounding diet. Nutritious diets may be prohibitively expensive or challenging to find. Many rural areas lack a population base large enough to support a grocery store with a variety of affordable and nutritious foods.[83] Rural families who rely on convenience stores are faced with high prices and limited selection of quality foods,[83] resulting in a greater burden of nutrition-related disease.[84] Additionally, participants noted comprehensive health education for girls and women may be difficult to access, further impacting patients' abilities to navigate optimal health behaviors in pregnancy. Structural constraints affecting patients' ability to adopt health-promoting behaviors have consequences to maternal health; poor health prior to the conception of pregnancy is associated with poor health during pregnancy and maternal morbidity.[7]

Participants also discussed how regional social and economic environments present further challenges surrounding the utilization of specialty care, as patients may struggle with expensive and time-consuming travel distances, inadequate postpartum insurance coverage, and possible class-based discrimination within healthcare. Such constraints also directly translate to increased risk of poor outcomes, as high-quality prenatal care and access to specialized obstetric care alleviate risk of SMM and PRM.[21]

When discussing the burden of poverty within their communities, some participants alluded to the economic history of the region. Some participants championed the resilient work ethic of their region, describing past generations as "really tough people" who "work their body down," and described pregnant women as performing physically demanding field work. In contrast, they described current generations as having an "almost a lazy culture." Participants directly related this shift to the elimination of tobacco subsidies and

decline in farming, and coal jobs leaving the area. Embedded within these discussions of poverty and resiliency is a valorization of work ethic, even when working environments were not necessarily conducive to optimal pregnancy health.

The value placed on work ethic also had implications to views of social stratifications, and the relationship between class and maternal health. Some participants viewed social welfare programs as grounds for social stratification, rather than a mechanism to alleviate social disparities, and differentiated between low-and middle-income individuals who received government assistance and individuals who did not. For these participants, the receipt of government assistance was a more significant differentiator of class than financial wealth.

In identifying determinants of SMM and PRM and directly positing strategies for future intervention, participants identified practical opportunities to alleviate SMM and PRM within their patient populations. In contrast to efforts to reduce PRM aimed at obstetric care providers (e.g., the development of "bundles" to standardize care for postpartum hemorrhage),[85] the points of intervention identified by participants extend beyond the healthcare sphere. Results inform a diverse range of intervention strategies that may be further investigated by a range of stakeholders.

Participants identified tangible points of intervention to alleviate maternal health disparities and promote community health (Table 3.1). Although some participants practiced in relatively populous Appalachian counties (i.e., with populations of 25,000 individuals), participants overwhelmingly identified rurality as a key characteristic of their patient population, and interventions reflected the challenges of providing obstetric care to rural women. In particular, strategies outlined by EMT participants represent focused and

finite goals for enhancing EMTs' ability to provide effective care. Some EMT participants challenged the effectiveness and feasibility of current EMS guidelines in their rural counties, theorizing certain policies that work well in densely populated areas may not translate well to rural communities. Some participants suggested policies and practices should be established with rural Appalachian communities in mind.

Policies concerning limitations in pre-hospital medication administration created unforeseen challenges for rural EMS compared to services in more populous areas for two principal reasons. First, EMS shortages are most severe among rural communities.[86, 87] They noted while services in more populous areas may have more paramedics on their teams, they were unable to run ambulances with two providers certified in ALS, restricting their ability to adequately treat. Second, an inability to adequately treat may have more severe consequences for rural patients due to longer travel times. The further distances to hospitals mean patients spender a greater length of time under the direct care of EMTs, potentially making pre-hospital care more critical.

Several participants championed the role of Community Paramedics (CP) programs in rural communities as a response to other systematic shortcomings. They voiced CP programs allows providers to establish trusting relationships with patients, provide patient education, and care for patients who may be limited by transportation, childcare, and financial constraints. CP programs are associated with clinically meaningful differences in patients' health, decreased need for intensive care, and decreased health costs.[88] In the participants' counties of practice, CP programs have not been enacted for the care of high-risk obstetric patients. The potential of CP programs to alleviate maternal health disparities warrants further study and reevaluation of current EMS reimbursement models.

Participants also spoke to the importance of extending Medicaid coverage to include a full post-partum year. Federal law currently requires pregnancy-related Medicaid coverage to extend to sixty days postpartum.[89] While some women may qualify for Medicaid through other pathways or receive Medicaid coverage for a full year through state-expanded Medicaid, other women do not receive this support.[89] Women may remain at risk for morbidity and mortality triggered by pregnancy throughout the first post-partum year,[90] with particular risk for maternal death secondary to self-harm.[91] Postpartum Medicaid expansion is associated with greater outpatient care utilization by women with significant morbidity events at delivery,[92] indicating the importance of insurance expansion for women with histories of SMM.

Although participants spoke to distinct aspects of Appalachian identity, findings from this study may be applicable to other populations of rural women, including more racially diverse rural communities. Nationally, rural Black women and rural Indigenous women experience greater burdens of maternal and perinatal morbidity compared to rural white women and urban Black and Indigenous women.[18, 29] These patterns indicate the need to address the intersection of race and place-based maternal health inequities. Points of intervention identified by participants may be impactful to racially minoritized rural women in Appalachia and beyond. For instance, expanding Medicaid coverage throughout the late post-partum period may have a particular impact on Black and Indigenous women, who utilize Medicaid coverage for pregnancy care at a greater rate than white women.[93]

In-depth interviews limit the generalizability of this study's findings to other patient populations. This manuscript focuses exclusively on providers' and EMTs' perspectives, and does not address the perspectives of other key stakeholders, including patients.

Findings from interviews with women with histories of SMM are documented in Chapter 4.

Many of the structural and intermediary determinants of SMM and PRM identified by participants are not specific to pregnancy. Enacting interventions outlined in Table 3.1 have the potential to impact health outcomes for a multitude of patient populations. Clinical commentary on maternal mortality has reasoned "a rising tide would lift all boats"[52] – efforts to broadly improve women's health and alleviate longstanding social inequities among minoritized and underserved populations would diminish rates of PRM and SMM.

Table 3.1 Intervention ideas proposed by research participants, organized by CSDH construct.

Construct		Select Quotes	Points of Intervention
Intermediary Determinants	Material Circumstances	"Sometimes we have to wait until the beginning of the month to try to get all the patients again when their phones are reset. So that definitely is a barrier. And you know, even internet. A lot of these women may, don't, they may not even have access to internet where they live if they're in a rural area."	• Expansion of affordable phone and internet services in rural Appalachian communities • Greater availability and affordability of nutritious foods to manage maternal disease states (i.e., diabetes, hypertension, and nutritional anemias)
	Substance Use Disorders in Pregnancy	"As far as addiction care, we're growing in the number of centers in the area for sure. It's still few and far between as they take pregnant patients." "…We also have worked really closely with a Hep-C coordinator and substance use MAT through [a local clinic]. So that's really great….We can at least get them in with our clinic so they're getting prenatal care and getting that substance use piece of it too."	• Integration of treatment services during prenatal visit • Expanded access of MAT for pregnant women • Extended follow-up for women with SUD in the post-partum period

Table 3.1 (continued)

Intermediary Determinants	Healthcare System	"Well, for one, if they could have more providers in the area that had, you know, a little more expertise on the subject…If you had a provider that came in here, even if they were just here one day a week and saw the people in this area, it would make a tremendous difference in the care that is provided." "…Most of our medical directors are emergency physicians, so they're not trained in obstetrics…I think it would be a really good idea if you can get some obstetric providers on board with our medical directors for the ambulance services, and say, 'Hey, how about paramedics be able to…do this procedure to help prevent these pregnancy complications.'…We really need to get some labor and delivery people on board to help expand our protocols with stuff like that." "The only thing I could think of that would be an easy first step would be…it would depend on jurisdictions and where you're at, who's involved, but a roundtable discussion. You know, a liaison from every agency, department, clinic, and someone to lead the discussion. So, the care can be better facilitated for these patients. And for us to say, 'If we show up on the scene with someone who doesn't have prenatal care, who do we direct those patients to and who's going to receive them?' and further that discussion." "…Would be so much more…convenient if your paramedics and EMTs and stuff had some more in-depth training to where they could handle some stuff that right now, they're not able to do legally-wise." "Especially, you know, in OB or pediatrics at all, in general, we're kind of set up to fail. And that's harsh to say, but we don't…it's kind of those high-risk, low-frequency calls that we go on. So, the most area…extremely high risk. But we just don't go on them all that much, and therefore we don't receive as much training on them." "I'd say there's some…a fair amount of benefit to simulation training. Even bringing OB docs out, or nurse midwives, that kind of stuff, and run scenarios…We can simulate it to the best of our ability. Doing that more annually would be very, very beneficial." "And just, you know…have a, keep them a plan specific to [a patient's] area. Like understand that you can't just show up at this hospital and expect to get quality OB care..."	• Collaborations between EMS leadership and obstetric care providers • Development of more extensive protocols for EMTs responding to obstetric emergencies • Continued clinical training in obstetric emergencies for EMTs (i.e., annual simulation training) • Evaluation of state EMS policies that limit the care EMTs can administer to pregnant women in rural settings • Expanded access to obstetric providers via regional telehealth or in-person outreach • Roundtable discussion with obstetric care stakeholders to identify standards of care for high-risk patients in rural settings • Development of individualized plans for patients during the prenatal period concerning when/where to present to care in case of emergency

Table 3.1 (continued)

Structural Determinants	Education	"I think it should be an education if they go to the health department or they try to seek care, there oughta be a "This is how it's gonna work. You need to follow up with this." Whatever. "If you have a problem, this is a problem" – tell them what the problems are – "then you need to go to the hospital." "I wish we had people who could be dietitian consultants through their pregnancy, which we do for our gestational diabetics…But I mean, that could be applicable for anybody with a BMI over 30 or 40. We could have a dietary consult, but we just don't have those kind of resources. That's number one. But number two is just basic education. So maybe this could be something within a public school system providing more education on healthy lifestyle. Contraception is not even discussed in [our county's] public schools, from what I understand…So I think that could be one step, just better education from the get-go."	• Collaborations with local school systems and county health departments to introduce comprehensive health curriculum for teens and young adults • Integrated prenatal education during prenatal appointments (i.e., opportunities to meet with a prenatal educator during a prenatal appointment while waiting to be seen by the obstetric provider) • Integrated consults with dieticians
	Economic and Social Policies	"If we're going to stay with the Medicaid model for most of our patients in this area, really extending that coverage out 6-12 months would allow them to not only to get contraception, but also if we did diagnose the chronic disease during their pregnancy, having them be able to get that taken care of in those first six to 12 months postpartum would be huge." "Community paramedicine in our area is not really geared towards pregnant women right now. It's more geared towards those patients who fall through the cracks…So community paramedicine, our program, they would schedule one to two meetings a week…So they basically were the lowest level of care, in-home care in the field." "[The Community Paramedics Program] would help for women who have transportation issues, women who just don't feel like they can go to a hospital. It would definitely fulfill a need. The issue would be that the state of Kentucky would have to buy into it, and then you would have to have insurance companies buy in for there to be a reimbursement program for that. Because right now, the only way you get money is if you go to the hospital."	• Expanded Medicaid coverage to 1-year post-partum • Economic investments in pregnant women and new mothers • Expansion of pilot Community Paramedic Programs for high-risk obstetric patients • Reevaluation EMS compensation system to allow for home visits

CHAPTER 4. QUALITATIVE INTERVIEWS WITH SEVERE MATERNAL MORBIDITY PATIENTS IN APPALACHIA

4.1 Introduction

Women in the United States (US) experience a disproportionate and rising risk of dying from pregnancy-related causes.[1] In 2018, an estimated 17 in 100,000 live births resulted in a maternal death, a ratio two to ten-fold that of other high-income countries.[94] This ratio continues to climb; pregnancy-related mortality (PRM), defined as the death of a woman during or within one year of pregnancy due to pregnancy-related complications or aggravated preexisting conditions, has nearly doubled since the turn of the 21st century in the US.[1]

Despite troubling epidemiological patterns, PRM is a rare event. Severe maternal morbidity (SMM) was coined in 1991 as a complementary indicator of obstetric outcomes, and has historically been used to assess "maternal near miss mortality."[95] Cases of SMM, defined as the occurrence of end-organ damage in the mother encompassing unexpected outcomes of labor and delivery that result in maternal health consequences, have climbed alongside cases of PRM and nearly tripled since 2000.[1, 2] For every woman who dies from pregnancy-related causes, an estimated 50-100 experience SMM.[96]

Patterns in the prevalence and etiology of SMM and PRM across the US reflect the consequences of patients' pre-pregnancy health, access to healthcare, and social determinants of health.[1] Women living in rural areas, women with common chronic illnesses, Black women, and Native American/Alaska Native women in the US have all been indicated to be at increased risk for PRM compared to national averages.[1, 2, 8, 35, 59, 72] Variability in the risk of death by disease states and sociodemographic factors demonstrates

more must be done to better elucidate determinants of SMM and PRM among health disparate populations.

Qualitative studies have explored patients' experiences with maternal morbidity.[97, 98] Patients maintain unique perspectives with value beyond their personal story, and qualitative research that engages patients is relevant to both study participants and future patients alike.[97] A synthesis of qualitative studies of women with SMM in the United Kingdom found women's experiences may be classified into three interconnected categories: the SMM event, the immediate reaction to having experienced the event, and the aftermath.[98] Perceptions of SMM were influenced by women's pre-pregnancy health conditions, availability of high-quality obstetric care, and social support network.[98] Qualitative studies with American women have highlighted feelings of powerlessness, fear, and guilt following morbidity events, as well as dissatisfaction with the amount of information offered by providers.[10]

Qualitative studies have focused on characterizing patients' experiences with SMM. Such studies have provided minimal insight into women's perspectives on the underlying causes of SMM, or their ideas on points of intervention to prevent SMM within their communities. This study employs qualitative methods to characterize determinants of SMM among an underserved and understudied patient population; namely, Appalachian women. The objective of this study is to characterizes Appalachian women's experiences with SMM, their perceptions on factors contributing to their disease course, and their suggestions for future points of intervention.

4.1.1 Maternal Health in Appalachia

Appalachian women are at elevated risk for SMM.[99] Health conditions prior to the conception of pregnancy are associated with poor health during pregnancy and poor maternal outcomes.[7] Appalachian women of childbearing age are in worse health prior to the conception of pregnancy, including higher rates of smoking, obesity, and poor nutrition compared to their non-Appalachian counterparts.[7] Appalachian women of childbearing age also report lower rates of health insurance and lower rates of annual check-ups with healthcare providers, which further expose them to poor pre-conception health.[7]

Appalachian women have fewer resources with respect to the detection of risks during prenatal care and the delivery of emergency obstetric care when complications arise. Availability of specialty physicians, including obstetricians and high risk maternal-fetal specialists, is 65% lower in rural and economically distressed areas of Appalachia compared to the country as a whole.[34] These disparities indicate critical barriers may exist concerning proper risk assessment and crisis management.

4.2 Methods

4.2.1 Theoretical Framework

This study was in part guided by a phemonological approach, which distinguishes between an etic perspective of an outside observer, and the emic perspective of a study participant with direct experiences. Namely, this study relies on insights directly provided by Appalachian patients with histories of SMM. Through this approach, this study employs in-depth interviews to examine Appalachian patients' experiences with SMM, perspectives

on the underlying determinants of their severe complications, and insights into future points of intervention.

Interview questions and data analysis were guided by the conceptual framework for action on the social determinants of health adopted by the World Health Organization (WHO) Commission on the Social Determinants of Health (i.e., the CSDH framework). By synthesizing numerous frameworks of the social determinants of health, the CSDH framework provides a comprehensive conceptual tool that may be used to guide empirical work, identify determinants underlying disparate health outcomes, and ascertain points of intervention.

Creators of the CSDH framework hypothesize the social gradient of health is caused by an unequal distribution of power, income, and services, resulting in downstream inequities in individuals' immediate living conditions. The CSDH framework consists of *intermediate* and *structural* determinants. Intermediate determinants define an individual's place within social hierarchies based on their social status, and exposure to both health-compromising and health-promoting environments. Intermediate determinants include material resources available to an individual, biologic and psychosocial risk factors, and the local healthcare system. Structural determinants generate social stratification and maintain an individuals' position within a social hierarchy. Structural determinants involve an individual's socioeconomic position based on class, education, race, and gender. Structural determinants also involve the social, economic, and political contexts that define an individual's socioeconomic position. The CSDH framework defines *context* broadly to include all social, economic, and political mechanisms that generate and maintain social hierarchies.

Additionally, the CSDH framework acknowledges a feedback loop between illness and upstream determinants. An illness may impact an individual's intermediate determinants, such as their material circumstances or health behaviors. An illness may also impact their socioeconomic position, such as their employment status or income. Moreover, prevalent illnesses within populations may also impact cultural values as well as social, economic, and political policies.

In sum, the CSDH framework encourages researchers to study the material limitations of individuals' lives, as well as the social, economic, and political policies that influence the distribution of health-damaging and health-promoting experiences. By identifying patients' social contexts and differential vulnerability, the CSDH framework highlights distinct levels and mechanisms of causation resulting in health inequity.[47, 48] By framing health as an outcome of social phenomena, the CSDH framework may be used as a tool to promote health equity, and recognize health disparities as manifestations of social injustice.

The CSDH framework has been used to synthesize current literature on the social determinants of maternal mortality in the United States, and identify potential areas of clinical and public health interventions.[49] This study seeks to address current gaps in literature concerning how structural constructs influence disparate rates of SMM and PRM within an at-risk population.[49]

4.2.2 Setting and Participants

This study examines SMM and PRM in the context of a predominantly rural Appalachia population. Rural Appalachian women fit the NIH criteria for a health disparate population due to their underserved rural status and high disease burden,[73] and embody multiple known risk factors for poor maternal pregnancy outcomes.[74]

The PI (AH) conducted interviews with ten Appalachian women who experienced SMM. Individuals were eligible to participate if: they had a self-reported diagnosis meeting SMM criteria, if they resided in an Appalachian county (as defined by the Appalachian Regional Commission) at the time of their SMM experience, and were at least 18 years of age, and were comfortable conversing in English. Women were excluded if any of these criteria were not met.

Appalachian women with histories of SMM were recruited in-person through University of Kentucky obstetric clinic and inpatient service. In addition, remote recruitment occurred via paper fliers in University of Kentucky clinics, virtual fliers on the University of Kentucky Center for Clinical and Translational Sciences (UK CCTS) website and UK CCTS social media. Individuals interested in the study could either submit an online form indicating their interest, or contact study personnel through information supplied by the flier. Patients recruited remotely were screened by the PI for eligibility. Patients recruited remotely were deemed eligible given self-reported medical histories of SMM.

2.3 Data collection

All interviews were conducted by the study PI; an PhD candidate in sociology, MD/PhD student at a large public university in Kentucky, and Kentucky resident of 18 years (AH). In light of the COVID-19 pandemic, all interviews were conducted remotely. Participants decided on a medium of communication (i.e., phone or Zoom) and time for the interview. Interviews lasted approximately one hour. Participants were compensated fifty dollars. Select questions are listed in Table 4.1.

4.2.3 Data analysis

Interviews were recorded with participants' consent and transcribed verbatim by the PI. NVivo software facilitated qualitative analysis. Transcripts were analyzed using inductive coding, a strategy which identifies patterned responses directly from the data.[79] To enhance rigor, two coders independently reviewed interview transcripts, proposed an initial codebook, and established an initial coding protocol. Memos within NVivo software documented the identification of new themes and enhanced data interpretation. The coders established an inter-rater reliability of $K \geq 0.8$. Analysis continued until team members reached thematic saturation (i.e. incoming data produced little new information to address the research question).[80] Following content analysis, the authors organized themes according to the CSDH framework (i.e. intermediary and structural determinants).

4.2.4 Ethics and Consent

The consent process involved a cover letter explaining the aims of the study, descriptions of the interview process, possible risks of participation, and information concerning the study's funding. Each participant was emailed the cover letter prior to the interview. Before beginning the interview, the PI reviewed the cover letter with the

participant and addressed questions. Consent was obtained once the cover letter was thoroughly reviewed and the participant affirmed (i.e., a verbalized "yes") that continued participation indicated consent. Ethical approval was granted by the University of Kentucky institutional review board and participants were protected by a federal Certificate of Confidentiality. Throughout the results section, participants are identified by pseudonym to protect their identity.

4.3 Findings

4.3.1 Participant demographics

The mean age of participants at the time of SMM was 28 (SD=5.5, Range: 23-37). Aligning with the racial/ethnic composition of Appalachian counties in this Southern state, nine women identified as white, and one identified as African American. No women identified as Hispanic. Concerning participants' highest level of educational attainment, one woman reported completing less than high school, one reported graduating high school, four reported attending some college, and four reported graduating from college or completing an associate degree. No women reported completing more than a college degree. Half of women reported being single at the time of SMM, and half were married. All women reported having health insurance at the time of their SMM experience; four had private insurance, and six had Medicaid.

Participants reported a mean number of three pregnancies (range: 1-6) and two living children (range: 0-5). Nine women reported SMM events in one pregnancy, and one reported SMM in two.

4.3.2 Patient Experiences with SMM

Women's clinical criteria for SMM spanned diverse diagnoses and procedures, including cardiac arrest, acute heart failure, disseminated intravascular coagulation (DIC), blood transfusions and emergent hysterectomy. Patients often reported several clinically related diagnostic and procedural criteria for SMM (e.g., cardiac arrest and ventilation.)

When describing the events leading up to their delivery hospitalizations, many women were not able to recount their experiences in full detail due to periods of unconsciousness or altered mental status. Alyssa explained,

> Honest, I really don't remember. Only thing I 'member was…um…they take me back…And I lost a lot blood. And…that's the only thing I 'member. And I was in bad shape…Med Flight [transported me]…No, I do not 'member half of it.

Grace similarly noted she was unable to remember any details of delivery or her first week of hospitalization following the vaginal delivery of her daughter and ensuing cardiac arrest:

> I ended up having [my daughter], which my mom has pictures of me, still up right after I had her…But my mom said that she saw me deteriorate right after I had her, and that's when I coded…I don't remember being out the first week. I don't remember nothing really of that week. Once they took me off the vent and everything. One after another. Once I got off the vent and off all the machines and stuff, I remember bits and pieces now of just me being in the hospital. But not much.

Consistent with prior qualitative work focused on women's SMM experiences, participants reported feelings of confusion, frustration, grief, and suffering.[98, 100] For many women, such feelings arose once their medical conditions had stabilized. Amber described her experience being extubated following a week of extracorporeal membrane oxygenation, and learning her daughter had died at delivery: "It was hard…yeah, it

was…waking up to that was a whole different thing." She went on to describe shared feelings of "anger" and grief with her family members present during her hospitalization.

4.3.3 Intermediary Determinants

4.3.3.1 Overview

The following section introduces a range of intermediary factors influencing Appalachian women's risk of experiencing SMM: transportation, social support, challenges surrounding childcare, biological factors, psychological factors, and healthcare system factors. Participants often discussed these factors as intertwined with one another, creating a complex and nuanced risk profile, rather than existing as isolated and discreet determinants.

4.3.3.2 Transportation

Consistent with prior research,[101, 102] participants described the importance of reliable transportation when seeking prenatal care, especially when frequent follow-up was necessary, and services were located further away. Although all participants reported access to cars, participants still commented on difficulty surrounding travel, especially when presenting with severe complications. Two participants described traveling through perilous weather conditions through mountainous roads to present for care. Denise explained,

> [Home] County is actually only one county away, so it wasn't too difficult to get to [my normal OB/GYN] as needed. But I feel like with [high-risk pregnancy], it's two hours away, so if something like the weather, like the snow we've had, it was harder to get there. And I know I needed to, but I just couldn't get out.

Two other participants' experiences with SMM required transportation via emergency helicopter due to the urgency of their conditions and the inability to provide adequate care locally. Others mentioned that although they were able to travel by car to necessary appointments, additional travel to distant clinics with high-risk specialists or post-partum appointments were challenging. One participant, Alyssa,[2] described travel to post-partum appointments as prohibitively difficult, and identified this as a cause in a lapse in contraception and current unanticipated pregnancy.

4.3.3.3 Social Support

Extended family, especially the mothers of some participants, provided essential support and advocacy for some participants. Grace expressed, "I felt like that if my mom wouldn't have been there, that I don't know if I would be here today… her and my brother, they really pushed for a lot…and they're still here supporting me today."

In contrast, some participants noted familial pressures limited their abilities to seek care outside their local hospitals. Amber explained her family's trust towards a provider who had delivered multiple generations of family members; "The roadblock with me wasn't that…I didn't have the finances, or the car to get somewhere to a high-risk doctor. It was the fact that I was young, I was naïve, and I trusted him." Two participants noted they or their families had professional ties to the hospital in which they received care, which carried additional pressure to present locally.

[2] All names provided in the results section are pseudonyms to protect the identity of participants.

4.3.3.4 Challenges Surrounding Childcare

Participants described the importance of familial support when discussing their childcare responsibilities. Participants who had children at the time of their SMM experiences often discussed the importance of partners and extended family networks, who were able to provide childcare during extended hospitalizations. While Kaylee noted it was emotionally difficult to be separated from her children while hospitalized, her extended family provided crucial childcare support:

> I am lucky to have a ton of…my husband has a ton of family. And his parents actually took my other two [children] for the three weeks that I was in the hospital. So, I never had to worry about if they were being taken care of. I just didn't get to see them. I think I saw them twice in three weeks.

Alyssa noted her mother lived with her during her prior experience with SMM, and was able to care for her other children. In her current situation, due to deliver another child in the near future, she noted less support; "My mom was helping me too. I had my mom, my daddy, and one of my sisters, and one of my brothers…[But] when I have this one, my mom don't live with me no more, and my old man don't be with me at the hospital when I have this one." She noted the lack of family around this time made her situation more complicated and difficult.

Autumn described severe challenges surrounding childcare following her hospitalization in a cardiovascular intensive care unit. She described circumstances in which childcare responsibilities directly conflicted with her acute medical needs. Her situation culminated in her leaving the hospital against medical advice because nobody was available to care for her children:

> I actually checked myself out from [the hospital] against medical advice [over the summer] because school started back in nine days. We had babysitters set up after school started back, and I could've spent the rest of the time in the hospital, and that was fine. I just needed those nine days.

4.3.3.5 Biological Determinants

Multiple participants noted preexisting illnesses prior to their pregnancies. Participants noted prior histories of chronic hypertension, diabetes mellitus, thyroid disease and opioid use disorder (OUD). For women with hypertension, diabetes, and thyroid disease, participants expressed that their providers discussed their preexisting illnesses during their prenatal visits, and implications for pregnancy complications. Denise explained, "Well, actually they told me that, which I knew I had high blood pressure in my teenage years, but it didn't seem that bad. I didn't know that I had high blood pressure when I was 14, so I just, they talked to me about that." Despite the counseling women received about their preexisting illnesses, participants rarely noted them as significant contributing factors to their SMM experiences.

4.3.3.6 Psychological Factors

Although participants did not identify mental health issues as contributing to their SMM experiences, several discussed mental health challenges after SMM and the postpartum period. Some participants described experiences with psychological distress following their SMM experiences, ranging from severe postpartum depression (PPD) to feelings of grief, guilt and confusion. Hailey reflected on long-term psychological sequela of her complications, which led her to seek inpatient psychiatric care following her discharge from the obstetric unit. In particular, she reported severe distress surrounding her

loss of fertility after requiring an emergent hysterectomy. Jess spoke openly about her experience with PPD. She described challenges surrounding mental health care, especially for younger women:

> I know moms, especially younger moms – they don't have to be specifically teens, but 25 and younger – who, it's their first kid, and then they decide to go to therapy or ask for help. And they're made to feel like crap, because 'Well, you put yourself in [that] situation, and you're going to have to deal with it.'

4.3.3.7 Relationship and Communication with Healthcare Team

Participants had diverse perceptions on the quality of communication with their healthcare providers, ranging from highly supportive to actively detrimental. Some described their healthcare providers as communicative and empathetic. Janeen described becoming established with her physician as "pure luck or divine intervention. I believe it was divine intervention." When asked about her provider, Autumn explained, "I loved him…For me, he was perfect… he didn't sugarcoat, but he didn't scare me, you know what I mean? Like I don't want…don't sugarcoat it, tell me what's going to happen." Denise similarly explained, "I just felt like the doctors and most of the nurses that I had, they really communicated with me well and wanted to see that I was okay." She went on to note her nurses were "really hands-on, were very calming and understanding and…I feel like even they were supportive."

Despite these perceptions of her healthcare team, Denise noted the high volume of providers entering her room when hospitalized was overwhelming; "I'm really glad so many people care, but I feel like when you're really going through health problems, I feel like too many people in the room doctor-wise, it's really stressful to make important

decisions about what needs to happen, or maybe speak up to your doctor about certain things."

In contrast, others described communication as insufficient, or even harmful. Faith questioned the degree to which her provider listened to her when she presented at 32 weeks' gestation, concerned about swelling in her face and a severe headache:

> I think I felt like maybe they didn't listen to me as much because of my anxiety. And I felt like maybe, that had they really listened to me earlier that day when I went to the hospital, that maybe things would have done been done a little bit different. You know, there's times where I sit back and I think, you know, "Did he really listen to me? Or did he just think, 'oh…' 'cause I remember him telling one of the nurses 'she's anxious, let's get her out of this labor room, and let's move her to a private room.' And they did that, but in the scheme…you know, in the time that it took to do that, then my levels crashed even more.

Grace attributed the severity of her SMM experience, which resulted in a one-week period of extracorporeal life support and the intrauterine death of her 37-week infant, on her provider's dismissal of symptoms. "I felt like my symptoms and my concerns were gaslighted by him," she explained. She elaborated:

> You go in [to your prenatal appointment], you're not educated. You have a question here and there, but as far as really legitimate concerns or whatever, I feel like, again, they're gaslighted, or just swept under the rug. Like, 'that's not really it,' or 'that's rare.' 'It's normal. It's normal' – that's what I heard from him.

4.3.3.8 Access to Healthcare Resources

Some women explained how living in a rural location complicated access to specialty care, and believed the nearest clinical sites provided inadequate care. "There's no resources. There's nothing. In this area, there's nothing big," Kaylee explained. She went on to elaborate:

> We have to travel three to four hours away to get any kind of help, really. You just get the basics here. If you have anything past that, then you have to go somewhere else. There's nothing really here, just…you just hope that you have nothing serious, really...We end up at the hospitals or the doctor's offices that don't provide anything.

Jess explained, "I know almost everybody avoids our local hospital if they can…I mean it's not even a Band-Aid shop." Kaylee also described the lack of specialty care; "I mean, not everybody can have one doctor from every specialty for every organ or possible situation on hand during a routine C-section or a routine birth, just in case."

One participant noted a lack of contraceptive counseling and options as detrimental to her health. She reported wanting a tubal ligation after her last pregnancy, but nobody discussed the option with her until "the last minute, [after] they stitched me up." She was pregnant again at the time of her interview, and explained the unanticipated current pregnancy came with significant fear due to her previous experience with severe post-partum hemorrhage, "When I have this kid, I might not even know what happens at the last minute," she explained. "I really don't know what to do now…I told my old man…I can die from it, 'cause the doctor told me, if I have one more, I can die."

One participant was seen via telehealth services by a high-risk maternal-fetal medicine service located two-and-a-half hours from her home. She noted, "My OB did make sure that I did see them once a month. Which, it helped relieve stress, because I was…I had other eyes looking at my situation too, other than just my doctor. So, I did feel like that helped me."

4.3.4 Structural Determinants

When discussing causes of their SMM experiences, women often theorized about systemic problems rather than considering their experiences isolated events. In particular, participants identified diverse biases within the healthcare setting they believed detrimentally impact maternal health. Additionally, they discussed how living in rural communities presents unique constraints on the opportunity to engage with their healthcare.

4.3.4.1 Stigma and Bias Within the Healthcare Setting

Underlying participants' descriptions of misdiagnosis and dismissal were the perception of discrimination and bias. When describing their experiences with healthcare providers, participants identified several factors they believed led their healthcare providers to undervalue their symptoms. "I feel like a lot of women don't get listened to there, around here…just because of their background," Grace explained. Participants provided diverse insight into which factors from women's backgrounds they believed were subject to judgement and influenced their care. In particular, participants discussed how history of substance use, rural identity, and social class impact women's decision to seek care and the quality of care they receive upon presentation.

Grace attributed her experience with sudden cardiac arrest and undiagnosed peripartum cardiomyopathy to her provider's bias against women with opioid use disorders. "There's a lot of mothers out here now that are in these [Suboxone] clinics that are trying to get help, but there's a lot being dismissed for medical reasons, like doctors

aren't paying attention because they are looking at them in a different way," she explained. She went on to say:

> At my doctor's appointment, instead of looking at me as someone on Suboxone when I'm pregnant, they shouldn't have even…I feel like they shouldn't even be allowed to look at someone that way. You can't change nobody's opinions or nothing, and I feel like maybe, maybe…I want to find some way to open [local healthcare provider]'s eyes to realize that these women out here, all they're doing is making it harder for them to seek attention or want to seek attention.

Although Jess did not herself have a substance use disorder (SUD), she noted her mother and sister both had SUDs, and described significant biases among local healthcare providers towards women presenting with pain. "But they see so many drug seeking people that I think that they assume everybody is drug seeking," she explained.

Others described how they may be treated differently based on their social class. Faith specifically identified "socioeconomic" status as a source of discrimination, while Amber noted "poverty." Jess stated, "If you're a low-income family that comes in with a Medicaid card, y'all are usually going to be treated like crap." Other participants focused discussions of class around physical appearances. Kaylee explained, "Around here, if you go into a doctor's office and you're not cleaned up, dressed up or anything, you don't get the care or the attention that you need. If you're not clean, or you have not the best clothes on, or dirty clothes, you kind of get pushed aside, or just looked over here."

Alongside visual appearances, others noted an auditory component, and believed their accents introduced additional bias. They described their regional accents as associated with low educational attainment and poverty. Amber explained:

> I think there's a level of discrimination with rural areas…of course I'm going to say Appalachia, because I'm here, but this is a rural and Appalachia [area], so both

> of them…Born here, I feel like I have such a thick accent…I feel like…the people, other people – healthcare workers, mainly – discriminate on the fact that they hear me, and they think I'm…I don't want to say '*stupid*,' but that I don't really know what I'm talking about. I feel like maybe…women that are pregnant in, maybe they want to go somewhere else. Maybe they…you know, in the back of their mind, maybe I should go to this high-risk doctor, but I don't want them to think, you know…'a woman from the hills, barefoot and pregnant, don't know what I'm talking about, I'm just overreacting.'

Amber went on to reflect on her vulnerability as a young, single pregnant woman in her rural Appalachian community, noting, "I was a statistic. I was young, not married, pregnant. And I went to a doctor I trusted, and all this happened."

When asked about her perceptions of discrimination, Janeen described broader biases against rural Appalachian patients as a whole. She noted that although providers ranged broadly in their ability to communicate with and advocate for patients, many assumed a paternalistic role. She described:

> Not all, but a lot of physicians who come to Appalachia, specifically within the southeastern Kentucky region…[in] the more rural areas of Appalachia …I think a lot of them are just very arrogant, and I understand the phrase 'God-like complex' or 'God complex.' Because there's some fantastic doctors who have like medical knowledge, are like, 'listen, yes, I want to educate, to teach you.' But there's [some doctors]… they just think that they should, well, 'I know what I'm talking about, the one with a degree in medicine, so you should just shut up and listen to me.' I think you encounter a lot of that within our culture, in our region.

Participants identified concrete consequences of discrimination within the healthcare setting. Namely, they associated provider bias with fears of being dismissed and made to feel as if they were "crying wolf again." Faith explained,

> I feel like sometimes they kind of take a step back and just say, 'Oh, okay, I'm just going to ignore this symptom because they're gonna think I'm crazy. They're gonna think I'm being anxious. They're gonna think I'm just…' But, you know, then that may be the problem. They may be truly having a problem then.

When questioned about discrimination, some participants noted they associated discrimination with race. However, given the sample of this study was 90% non-Hispanic white, the majority of participants were unable to comment on personal experiences with racial biases in healthcare. When questioned about whether she had experienced any discrimination in a healthcare setting, the sole participant who identified as African American reported no instances of discrimination within her healthcare team; “I haven’t had anything happen to me at all,” she noted, “But somebody else could think something totally different from me.”

4.3.4.2 Economic Context

The economic context of communities compounded individual financial constraints, further complicating participants’ ability to engage with high quality obstetric care and access comprehensive health education. Often, participants’ insights extended into the social and economic landscapes of their hometowns. Participants noted widespread poverty in their areas; “Around here, there’s no wealthy people.” Kaylee noted, adding, “Nobody has money.” Denise described her rural status as “isolation,” also noting there were “maybe not as many advantages.”

Most participants noted prenatal care was available in their area – if not in their county, then in an adjacent county. However, they questioned the quality of the available care, and moreover, their potential to engage with it. Amber noted the burden of poverty in her area, but also explained, “It’s not just financial poverty. You know, it’s access, even in the area of having access to your phone, all these things online, education – we don’t, it’s just not there.”

4.3.4.3 Patient Agency

Some women noted significant paternalism within healthcare, describing a culture of care in which they were expected to trust the judgement of the healthcare provider without playing an active role. Amber described, “You go to the doctor, and you just, you don’t really have any input. You just listen to them. Like they…there’s not a lot of…not that there’s not *access* to healthcare, like there’s none here, but it’s like…you go in, [but] you’re not educated.”

Other participants provided contrasting perspectives, and felt engaged with their care. “My providers did a lot of education,” Faith said. However, she also described other women in her area may value the knowledge and experience of the women in their families when navigating medical decisions, even when such information contrasts with their prenatal care. “They may not take their prenatal care serious or feel like it's needed because, you know, if they can't get there [due] to transportation, then…grandma or mamaw will [say], ‘Oh, well I did this with my pregnancy.’ So, then they just like go with that.”

Denise also endorsed that she was able to engage with her healthcare, stating; “Yes, I think I could [ask questions]. I just feel like I didn’t have the right questions, or if I did, there were no answers.” Her response may also highlight stressors related to the lack of medical information on the etiologies of critical obstetric complications, including Denise’s diagnosis of peripartum cardiomyopathy.

4.3.4.4 Maternal Mortality and Intergenerational Trauma

Despite the relative rarity of SMM and PRM, multiple participants described how family histories of maternal mortality had molded their own experience in pregnancy.

Amber reported her mother had died at age 20 from pregnancy-related causes, and reflected on this history when recalling her experience losing her daughter at delivery:

> My aunt, she said it perfect. She said it was 'de ja vu all over again' from when I was born…on top of me being, they didn't know if I was going to live or die, they had my daughter who had died. You know, it had flip-flopped from my mom and me.

Jess also noted a history of maternal mortality. She explained, "I am actually the only person on my dad's side of the family, you know, 4 generations and 36 births that have survived a C-section." She noted her family was highly concerned when she began developing complications; "I mean I have told them that I had to have a C-section and my grandmother went ahead and call the funeral home and paid off that, and my dad checked his life insurance policy on me."

The experiences of Amber and Jess reflect how the trauma of maternal morbidity and mortality has a profound and persistent impact on patients' family. Participants' own experiences have a lasting impact on their family and community wellbeing.

4.4 Discussion

Certain findings from interviews highlight broad themes consistent with results from other qualitative studies of SMM patients across the US.[98, 100] Appalachian participants reported feelings of confusion, frustration, grief, and suffering, consistent with prior qualitative work focused on women's SMM experiences.[98, 100] Participants located in Appalachian communities placed an emphasis on comprehensive and compassionate communication with their providers, also consistent with prior findings in other regions of the U.S.[100] Their responses provide additional support for enhanced communication during

crisis situations.[103] Specifically, their perspectives highlight the postpartum period as an opportunity to debrief via recounting the childbirth experience through engaging in mental health counseling services and addressing the potential for long-term trauma.[104]

Participants distinguished between access to any obstetric care within their Appalachian communities, and access to care they deemed adequate. Participants did not view outright access to obstetric care as a challenge, describing available care at local and regional clinical sites. However, many described how local care did not adequately recognize, diagnosis, or treat their complications. From the perspective of women with poor outcomes in this qualitative study, this healthcare landscape resulted in misdiagnosis, potentially delayed intervention, and devastating, preventable morbidity. Underlying the perceived inadequacies in care were two distinct weaknesses: the lack of available specialty care required for high-risk pregnancies, and a culture of dismissiveness when patients present with symptoms of concern.

With outmigration to urban areas, rural hospitals do not have the patient population to support specialty services. Accessibility of obstetric care in rural areas is worsening, and rural communities are facing a decline in hospital-based obstetric services.[25, 26] A national survey demonstrated approximately half of rural hospitals do not provide obstetric care.[26] Between 2004-2014, the percent of rural hospitals with obstetric services fell from 54% to 45% due to hospital and obstetric unit closures, with more rapid rates of decline in the most remote counties.[25] Although rural depopulation places significant strain on small hospitals, some argue rural hospitals require significant investment, as they provide critical care for vulnerable, rural populations,[105] and serve as crucial economic engines for struggling communities.[106] Certain policy efforts may benefit rural hospitals and maternal health

alike. Most rural hospital closures have occurred in states that have not expanded Medicaid, in which healthcare costs for low-income patient populations may remain uncompensated.[106] Medicaid expansion efforts would also expand healthcare for women throughout the post-partum period, when they remain at risk for morbidity and mortality.[90]

However, in light of obstetric unit closures, telemedicine services provide an opportunity to introduce specialty care to rural prenatal clinics and hospitals. Telemedicine is defined as any health-related service that uses electronic communication methods to connect with a patient in a remote setting.[107] Telemedicine has been used in obstetrics and gynecology to provide a range of services, including perinatal care, maternal psychological care, and monitoring of high-risk obstetric conditions.[107] Telemedicine programs in rural communities are associated with improved maternal and neonatal obstetric outcomes,[108, 109] as well as enhanced perceptions of local hospitals and the implementation of innovative care models.[110] Although telemedicine obstetric services increased tremendously across the nation during the COVID-19 pandemic,[105] in recent years telemedicine services remained underutilized in Kentucky.[111] In 2019, specialized maternal-fetal medicine (MFM) outreach was present in only five of the twenty-one rural hospitals with low-volume obstetric units (<500 deliveries/year).[111] Although many participants were pregnant during the COVID-19 pandemic, only one participant noted utilization of telemedicine services, potentially highlighting the opportunity for telemedicine programming to expand regionally.

Telemedicine services may help alleviate certain key factors participants identified as contributing to and complicating their experiences with SMM. Telemedicine would connect patients with specialty care, as some participants wished they had had the

opportunity to do. Furthermore, it may reduce challenges surrounding transportation and assist with chronic disease management. Although no women identified mental illness as a contributing factor to SMM, some noted it complicated their postpartum course. Postpartum suicide is a leading cause of PRM,[112, 113] and telemedicine has been successfully implemented for maternal mental healthcare.[107]

Significant barriers may persist despite telemedicine expansion. Participants spoke extensively of the importance of thorough and empathetic communication with their providers, which may be complicated by remote technologies. Additionally, telemedicine may remain inaccessible for patients without reliable internet access or the privacy to use it. The closure of rural obstetric care units may further exacerbate access to specialty care, as community obstetricians often serve as the point of referral for telemedicine services. Additionally, some participants' greatest concern with the quality of their local obstetric care was their provider's dismissiveness of their concerns. If primary obstetric providers dismiss patients' concerns within their own clinical settings, they may be unlikely to connect patients with specialists via telemedicine. Moreover, although participants often felt favorably towards the specialists who provided obstetric care following their transfer from local hospitals, they may perceive the same dismissiveness and biases among high-risk providers. Some participants noted this concern, worrying that specialists would associate negative stereotypes with their accents and regional identity.

The most significant concerns raised among this sample of participants requires consideration of biases within healthcare surrounding patients' appearance, accent, insurance status, and past medical history. Implicit biases among healthcare providers contribute to inequitable quality of care, and can affect treatment strategies, patient's ability

to adhere to recommendations, and morbidity and mortality outcomes.[41] The importance of implicit bias training among obstetric care providers is gaining momentum.[114] However, these efforts remain limited to clinical interactions and delivery hospitalizations, and are not sufficient for addressing the systemic effects of bias. Shifting the culture of obstetric care so women do not feel "gaslighted" or "treated like crap" requires providers to not only refine clinical management, but to adopt a framework of health equity. Providers may act as medical "stewards," and promote health by working with other sectors to invest in social protection and foster advantageous environments.[115] Medical stewardship allows for the integration of social advocacy work alongside quality improvement initiatives, and health equity-oriented healthcare.[115]

4.5 Limitations

This study does not provide a representative sample of rural Appalachia, but rather provides in-depth perspectives on contributing factors to SMM in an at-risk population. In-depth interviews limit the generalizability of our study's findings to other communities, including those in other rural regions of the U.S. Recruitment of participants involved self-reported medical histories, so we are not able to report the detailed diagnoses for each participant. Additionally, SMM involves a diverse range of medical complications. Participants' experience with SMM may differ based on their particular diagnosis.

Recruitment methods may introduce volunteer bias, as women who volunteered for the study may differ in their experiences that women who chose not to. Despite this limitation, relying on volunteers allowed the study to enroll participants who were able and willing to discuss their largely traumatic SMM experiences. Additional bias may also have

been introduced due to technological access. Women without phone or internet service may have struggled to contact the PI.

This manuscript focuses exclusively on patients' perspectives, and does not address the perspectives of other stakeholders. Findings from interviews with obstetric care providers and emergency medical technicians are documented elsewhere (see Chapter 3).

4.6 Conclusions

Despite these limitations, this study uniquely contributes insight into the distinct experiences and challenges of SMM patients in largely rural, Appalachian communities. Through the perspective of patients, this study identifies both intermediary and structural determinants of SMM which may be targeted to alleviate maternal health disparities in an at-risk population. Future research may evaluate targeted interventions for this patient population.

CHAPTER 5. CONCLUSIONS

5.1 A Continued Case Study of Severe Maternal Morbidity in Appalachian Kentucky

Grace, who experienced a cardiac arrest at delivery, reflected on her postpartum experience. As the interview drew to a close, she contemplated her family. She mused over the history of her newborn daughter's name, her older daughter's joy at the new baby, her own mother's desire to keep her close. "My mom, she won't let me leave her sight now," she noted. "Which is okay with me, I understand."

As we said our goodbyes, she expressed her wishes for other women: "I just hope that...they don't get passed through the cracks, like they did me."

5.2 Summary

The aims of this dissertation were two-fold: (1) to examine patient-level and place-based predictors of severe maternal morbidity (SMM) and pregnancy-related mortality (PRM), with particular focus of how these factors influence maternal health within Appalachia, and (2) to characterize Appalachian healthcare providers' and patients' experiences with SMM, perceptions of determinants contributing to their disease course, and their suggestions for future points of intervention. This study directly responds to future directions proposed in a 2020 publication, which documented higher rates of PRM among rural women nationally, and outlined a theoretical risk profile for Appalachian women.[60]

This dissertation was informed by the conceptual framework for action on the social determinants of health adopted by the World Health Organization (WHO) Commission on the Social Determinants of Health (i.e. The CSDH framework), which seeks to highlight

distinct levels and mechanisms of causation resulting in health inequity.[47, 48] This framework involves the effect of intermediate factors, such as comorbid patient conditions, the material resources available to patients, and healthcare access. Additionally, it urges researchers to consider structural determinants, including the socioeconomic context in which such intermediate factors exist. The underlying social and economic contexts of patients' communities may influence an individual's degree of vulnerability, and the extent to which they are impacted by a poor outcome if one occurs.

Specifically, the CSDH framework was used in two ways. First, it informed the variables included in modeling in Chapter 2. Hierarchical logistic regression modeling facilitated the inclusion of patient-level predictors, as well as measures attempting to capture structural elements of patients' environments. Second, it informed the development of qualitative interview questions and analysis of results in Chapters 3 and 4. Importantly, the CSDH framework allowed the focus of this dissertation to expand beyond the study of clinical influences and consider the social settings in which patients live. For instance, the association between poor pre-pregnancy health and the risk of SMM is well-documented.[11] The CSDH framework facilitated novel threads of investigation. *Why are some women so predisposed to poor pre-pregnancy health?* Once a chronic illness is established, *why might they be more likely to suffer severe consequences? What structural determinants underly their inequities?* Hierarchical logistic regression modeling and qualitative interviews with a diverse group of stakeholders attempt to address such questions.

Findings identify critical factors that may be targeted points of intervention for pregnant and postpartum women in an underserved population. Additionally, findings demonstrate how both intermediate and structural risk factors critically impact maternal

health, including factors outside the clinical realm. Efforts to promote maternal health and reduce maternal mortality must reach beyond interventions targeting clinical management; efforts must engage with the social conditions in which women live. Lastly, this dissertation builds off previous work concerning the integration of medical and social needs within prenatal care. Findings highlight distinct challenges for medically and socially high-needs women living in largely rural Appalachian communities with limited options for care.

5.3 Identified Points of Intervention

This study's quantitative results provide further evidence that a patients' individual risk profile plays a critical role in predicting SMM. Consistent with past findings,[8, 11] maternal age and pre-pregnancy chronic disease states increase women's odds of experiencing SMM. In addition to individual-level predictors, results of this study highlight the importance of place-based social determinants of health. Risk factors for SMM extend beyond an individual's past medical history and clinical management, and into the social environment. Investigation of place-based social determinants of health may illuminate points of intervention which target not an individual patient, but the social context in which a patient lives. In particular, findings highlight local measures of economic security to predict SMM. Findings warrant further investigation to examine how addressing regional economic policy may enhance maternal health and alleviate disparities among women living in economically insecure regions.

Qualitative results echoed the effect of regional economic hardship on maternal health, as well as other diverse contributing factors. Participants discussed a connection

between dramatic changes in the socioeconomic landscapes of their communities and more proximal determinants of maternal health. Providers and EMTs discussed how socioeconomic contexts, such as limited employment opportunities, influence patients' socioeconomic position (e.g., class, education) and patients' material resources and health behaviors. They emphasized the social and economic environments of their communities impacted myriad proximal determinants of poor maternal health, including patient nutritional status, chronic disease states including substance use disorders, and underutilization of healthcare.

Women with histories of SMM provided unique insights from the patient perspective. Compared to providers and EMTs, women with histories of SMM assigned less importance to pre-existing illness and pre-pregnancy health. Instead, they pointed to limitations in local healthcare resources to adequately recognize, diagnosis, or treat their complications. Participants provided diverse perspectives on the quality of their local healthcare. However, in sum, they identified two distinct weaknesses: a lack of available specialty care required for high-risk pregnancies, and a culture of dismissiveness when patients present with symptoms of concern. When discussing providers' attitudes towards patients, women with histories of SMM also discussed the local economic landscape. Namely, they discussed the degree of poverty within their areas, and the biases within healthcare surrounding patients' reflections of class.

Counteracting bias against rural women, Appalachian women, and women of low socioeconomic status warrants tailored implicit bias training for clinicians. However, implicit bias training alone is insufficient, as such trainings are limited to clinical interactions and delivery hospitalizations, and do not address the systemic roots of bias

within healthcare. Shifting the culture of obstetric care requires providers and clinical leaders to adopt a framework of health equity. Specifically, providers must practice medical stewardship, and promote patient wellbeing by working alongside other sectors to invest in social protection and foster advantageous environments.[115]

5.4 Beyond Bundles: The Limitations of Clinical Interventions and the Need for Medical Stewardship

Over the past decade, recognition of significant disparities in maternal health spurred the development of new efforts to streamline the quality of obstetric care during crisis events.[116, 117] Leaders in obstetric care posited the key to alleviating maternal health disparities was to address maternal health*care* disparities present in critical minutes of crisis during severe morbidity events. In response to rising concerns surrounding obstetric health disparities, the American College of Obstetricians and Gynecologists (ACOG) launched the Safe Motherhood Initiative (SMI) in 2013.[116, 117] Members of the SMI developed care management plans (i.e., "bundles"), which provide standardized guidance to multidisciplinary clinical staff for the treatment of severe obstetric complications. Bundles are intended to reorganize evidence-based guidelines and materials in a manner which facilitates implementation in clinical settings.[85] Bundles provide standardized approaches to three leading causes of maternal death: hemorrhages, venous thromboembolisms, and hypertensive crises. The SMI promote bundles as an essential toolkit which provide comprehensive and standardized care management processes for patients at risk of maternal mortality. ACOG has collaborated closely with other organizations including the Alliance for Innovation on Maternal Health (AIM), a national evidence-based quality improvement initiative, to disseminate bundles.[117, 118] Bundle

dissemination and obstetric quality improvement initiatives have involved rural hospitals.[119] However, examination of such quality improvement efforts suggest greater consideration of the context in which hospitals' function, including rural status and institutional financial constraints, is warranted.[119]

The SMI, AIM, and other maternal care organizations acknowledge not all patients receive equal quality of obstetric care. By the launch of the SMI, research efforts had demonstrated inconsistencies in quality of care as a leading driver affecting maternal outcomes,[37] and inconsistencies in care were thought to be driving force of health disparities.[120] Differences in outcomes were considered reparable by optimizing providers' preparation for the inevitable crisis management. Within the obstetric community, health disparities were discussed interchangeably as health*care* disparities.[120] Standardizing approaches was identified as the key to reducing variation in care and improving disparate outcomes.[118]

Such efforts have been, in part, successful. California had more than 200 hospitals implement safety bundles, and has witnessed a 55% decline in the rate of maternal mortality, attributed to the streamlined interventions.[121] However, despite the significant improvements attributed to bundle implementation, disparate outcomes persist. For instance, although California's rate of maternal mortality was significantly lower than the national average in 2019, (17.9 versus 29.6 deaths per 100,000 live births), Black women exhibit rates nearly four times the state average (63.9 deaths per 100,000 live births).[122] Providers interviewed for this dissertation frequently noted the utility of bundles within their hospitals. However, they still noted the burden of severe complications and poor health among their patients.

Persistent disparities indicate the need for maternal mortality prevention to adopt a more expansive approach. Disparate outcomes in maternal health along social lines (e.g., by race, rural status, and regional identity) point to socially constructed underlying cause, as there exists no inherent genetic or physiologic reason such disparate patterns would persist. Alleviating high rates of maternal mortality within health disparate populations requires clinicians, advocates, and policy makers to confront the social conditions in which patients live, and adopt a framework of health equity.

To promote health equity, providers must act as responsible stewards for their patient population.[115] *Medical stewardship* describe the roles which may be taken by healthcare providers in collaboration with other sectors to promote equitable healthcare.[115] Shifting the focus of medical education to emphasize social determinants of health, prioritizing research that addresses fundamental causes of disease,[123] and partnering with other community stakeholders are key priorities for stewardship.[115] Traditional clinical programming has been largely unidimensional in its focus on medical need, leaving obstetric care providers inadequately equipped to care for social complexity.[124] By adopting a health equity framework and serving as medical stewards, physicians may play a role in alleviating not only heath*care* disparities, but health disparities rooted in longstanding social inequity.

5.5 Right-Sizing Prenatal Care for Appalachian Women

New models of prenatal care have attempted to add a second axis to risk assessment. Rather than dichotomize patients as either medically low or high-risk, patients may be further categorized by their level of "support" needs.[124] "Right-sizing prenatal care" posits

high-needs women receive the care they require, and allows low-needs patients greater care flexibility.[124] The framework for "right-sizing prenatal care" identifies four major phenotypes of patients, depending on relative medical and support needs. All women with SMM experiences may be considered medically high-need given the severity of their complications. Isolation, lack of previous prenatal education, and psychosocial stressors of many of this dissertation's participants may further classify some as high needs with respect to support. For patients with concomitant medical and support needs, proponents of right-sized prenatal care call for integrated social support services in prenatal care visits.[124] Specific strategies for addressing medically and socially high-needs women include increasing the number of prenatal visits, or providing care in a "pregnancy home" setting, which allows patients to see medical specialists and social support professionals during a single visit.[124]

Right-sizing prenatal care may help alleviate disparities in maternal health by addressing community-specific social determinants alongside medical complications. Clinicians and advocates have called for new models to be adaptable to "a wide range of geographic and health care settings."[124] However, current strategies for fulfilling the needs of medically and socially high-needs patients may be incompatible with the resources available in some rural communities. Findings from this dissertation highlighted difficulties in accessing distant specialist care and attending frequent clinical appointments, due to constraints on transportation, childcare, time, and finances. Recommendations for right-sizing prenatal care have focused on patient populations in urban areas, and have not yet accounted for the experiences of pregnant patients living in rural communities or embraced the growing role of telemedicine.

Additionally, some patient participants expressed concern over how they may be perceived by clinicians. (As one participant expressed, "…Maybe I should go to this high-risk doctor, but I don't want them to think, you know…'a woman from the hills, barefoot and pregnant, don't know what I'm talking about.'") Some participants expressed the view that clinicians judged and dismissed patients based on their socioeconomic status, appearance, rural residency, accent, and age. Such findings demonstrate further barriers for dual high-needs women seeking care in rural Appalachian communities. Effective care delivery requires shifts in patient-provider dynamics and addressing women's concerns surrounding their treatment in the clinical setting.

5.6 Conclusions and Future Directions

Findings from this mixed methods study illustrate diverse determinants of severe maternal pregnancy complications and poor maternal health, ranging from pre-pregnancy disease states to regional economic constraints with myriad downstream effects on community wellbeing. Many of the identified determinants of SMM and PRM are not unique to pregnancy; rather, SMM and PRM are particular manifestations of persistent and deeply seeded inequities. Efforts to broadly improve women's health and alleviate longstanding social inequities among minoritized and underserved populations would diminish rates of SMM and PRM. This study also highlights the role of medical stewardship among clinicians serving rural Appalachian obstetric patients.

Future intervention efforts must rely on frameworks of health equity, and involve investments with patients' communities. Interventions may include advocacy for Medicaid expansion, community paramedicine expansion, and the introduction of comprehensive

health education for rural Appalachian students. Such strategies highlight the importance of engaging with interventions outside the labor and delivery unit and prenatal clinic, and venturing into the broader community as stewards of medicine.

APPENDICES

APPENDIX 1.PLACE-BASED SOCIAL DETERMINANTS OF HEALTH IN APPALACHIA: A BRIEF REPORT

Introduction

Severe maternal morbidity (SMM) is a significant public health problem in the United States (US). The Centers for Disease Control and Prevention (CDC) define SMM as unexpected outcomes of labor and delivery resulting in significant short- or long-term consequences to a woman's health.[1] Epidemiologically, the CDC defines SMM using 21 diagnostic and procedural indicators which capture a range of morbidities, including disseminated intravascular coagulation (DIC), eclampsia, and acute myocardial infarction.[56]

Significant disparities in SMM burden exist for some populations of American women. Namely, Black, Hispanic, and Native women experience SMM at a disproportionate rate.[29, 57, 58] Rural women, low-income women and women living in certain geographic regions similarly experience higher rates of SMM.[59, 60] Despite a distinct risk profile for maternal morbidity and mortality, Appalachian women remain an understudied population.[74]

This study examines individual and place-based predictors of SMM among Appalachian women across the US. Appalachian Kentucky women experience an increased risk of SMM at delivery when controlling for common pre-pregnancy disease

states, race, maternal age, and rural status.[99] These results demonstrate further examination is needed concerning place-based predictors of SMM among Appalachian women.

The inclusion of place-based predictors in the following analyses is informed by the theoretical framework adopted by the World Health Organization's Commission on the Social Determinants of Health (i.e. the CSDH framework).[48] The CSDH framework posits that to understand and alleviate disparate health outcomes, consideration of individual risk factors alone is inadequate. Structural factors, such as the socioeconomic context in which patients live and other place-based factors, are crucial determinants of disparate health outcomes. Structural determinants, according to the CSDH framework, mold the differential vulnerability and differential consequences experienced by patients.[48]

A 2020 systematic review used the CSDH framework to examine the current state of maternal mortality research in the US.[50] This review called for greater examination of the relationship between socioeconomic factors and poor maternal health regional differences in maternal morbidity and mortality.[50] This study addresses these limitations by examining understudied structural constructs within Appalachia.

Methods

Although the increasing incidence of SMM in the US is well-documented, challenges arise when surveilling postpartum outcomes. This study utilizes a national sample of women's delivery hospitalizations from 2016-2018 linked to inpatient and emergency department encounters throughout the first post-partum year. This study discusses how both individual-and contextual, place-based risk factors influence women's risk for SMM throughout the post-partum period.

This paper conducts a retrospective analysis of a national sample of females aged 12-55 with documented delivery hospitalizations in the MarketScan Research Database between 2016 and 2017, and one-year of post-partum inpatients and emergency department encounters from 2017-2018. MarketScan includes data on patients across the US and is nationally representative for covered populations. Documentation for each encounter includes ICD-10 diagnosis codes, Current Procedural Terminology (CPT) procedure codes, age, and geographic indicators of patient residence. For further information on the MarketScan Research Database, see Chapter 2.

Delivery hospitalizations within MarketScan were identified using ICD-10 inclusion and exclusion criteria defined by the Alliance for Innovation on Maternal Health.[64] ICD-10-Procedure Coding System (PCS) codes were translated to CPT codes with the help of a professional medical coder at the University of Kentucky. Use of this database for these analyses was approved by the institutional review board at the University of Kentucky.

Variables of Interest

Outcome

SMM events were identified using CDC ICD-10 criteria and CPT coding. SMM was measured dichotomously, with the presence of any SMM indicator constituting an SMM event.[56]

Predictors

Predictors of SMM included individual risk factors assigned to each patient and place-based risk factors assigned to the metropolitan statistical area (MSA) of each

patient's home residence at the time of delivery. Individual patients were nested within the MSA of their home residence. An MSA is a core area containing a population "nucleus" and surrounding communities with a high degree of social and economic integration.[66]

Individual-level risk factors included maternal age at delivery chronic diseases associated with SMM.[8] Chronic diseases were identified using established definitions of ICD-10 diagnosis codes.[65]

MSA-level risk factors included the Social Determinants of Health Index (SDOHi) and Appalachian residency at delivery. The SDOHi provided a comprehensive measuring of place-based risk factors. The SDOHi is derived from place-based data elements from the American Community Survey, the US Department of Agriculture, the CDC, and other national data sources. The SDOHi is comprised of measures of healthcare access, food access, resources access, housing, transportation, and economic security, and provides a numerical value to each MSA. Additional measures are available through component indexes of the SDOHi including economic security, resource accessibility, physician density, obstetrician-gynecologists (OB/GYN) density, and pediatrician density.

Statistical Analyses

The proportion of individuals who experienced SMM was compared between Appalachian and non-Appalachian women. Next, the distribution of demographic characteristics and chronic disease states among patients hospitalized for delivery were compared between Appalachian and non-Appalachian individuals. Mean SDOHi scores and component measures were additionally compared between Appalachian and non-Appalachian MSAs.

Next, hierarchical logistic regression was used to model predictors of SMM at delivery and throughout the first postpartum year. Prior analyses have yielded a significant random intercept when nesting individuals within the MSA of their home residence, demonstrating the suitability of hierarchical modeling (see Chapter 2). Predictors included individual-level risk factors, as well as SDOHi measures and Appalachian status as MSA-level predictors.

Statistical significance was determined at an alpha level of 0.05. All analyses were conducted using Stata v.16.0. The final sample consisted of 281,495 women. Within the sample 228,514 had documented MSA data. Individuals without MSA information were included in bivariate and descriptive analyses, but excluded from the regression models. Women with multiple delivery hospitalizations within the study period were not excluded; all available data for these women were included in analyses.

Results

Descriptive results of the sample as a whole are reported elsewhere (see Chapter 2). Only 4.01% of the sample were Appalachian residents. The rate of SMM among Appalachian individuals was 0.63% compared to 0.57% of non-Appalachian individuals, although this difference was not significant.

The age distribution of individuals differed significantly between Appalachian and non-Appalachian individuals, with Appalachian individuals trending younger (Table A1). No significant differences existed in chronic disease burden by Appalachian residency.

Table A1. Bivariate analysis between patient-level predictors of SMM and Appalachian residency.

Characteristic	**Appalachian Individuals N(%)**	**Non-Appalachian Individuals N(%)**	
Maternal age			P<0.001
<18	56 (0.50%)	1,126 (0.42%)	
18-25	2,766 (24.52%)	52,004 (19.25%)	
26-35	7,151 (63.40%)	173,301 (64.13%)	
36-40	1,120 (9.93%)	37,518 (13.88%)	
>40	186 (1.65%)	6,267 (2.32%)	
Chronic hypertension	58 (0.51%)	1,386 (0.51%)	P=0.99
Pre-existing diabetes	92 (0.82%)	1,933 (0.72%)	P=0.22
Substance use disorder	45 (0.40%)	869 (0.32%)	P=0.16
Chronic respiratory disease	359 (3.18%)	8,230 (3.05%)	P=0.41
Chronic renal disease	5 (0.04%)	162 (0.06%)	P=0.50
Chronic liver disease	10 (0.09%)	384 (0.14%)	P=0.14
Chronic heart disease	45 (0.40%)	1,112 (0.41%)	P=0.84

The mean SDOHi score across MSAs was 53.19 (SD=3.51). Table A2 reports MSA characteristics of Appalachian and non-Appalachian MSAs. Appalachian MSAs had lower mean SDOHi scores compared to non-Appalachian MSAs (51.59 versus 53.42; $p<0.05$). Appalachian MSAs also had low mean economic security scores compared to non-Appalachian MSAs (49.86 versus 51.64; $p<0.05$). No significant differences were present when comparing physician density, OB/GYN density, or pediatrician density.

Table A2. SDOHi and component measure scores between Appalachian and non-Appalachian MSAs.

	Appalachian MSAs [Mean (SE)]	**Non-Appalachian MSAs** [Mean (SE)]	**P-value**
SDOHi	51.59 (0.31)	53.42 (0.20)	<0.01
Economic Security	49.86 (0.54)	51.64 (0.29)	0.01
Elements of Healthcare Accessibility			
Physician density	2.58 (0.23)	2.55 (0.09)	0.90
Density of OB/GYNs	0.11 (0.01)	0.11 (0.003)	0.93
Density of pediatricians	0.14 (0.01)	0.15 (0.005)	0.42

Rates of SMM did not differ significantly between Appalachian and non-Appalachian women (0.63% versus 0.57% respectively, p=0.44). As previously reported, the SDOHi and economic security were significantly associated with SMM, with decreased scores of both measures predictive of higher SMM risk (see Chapter 2).

Results from hierarchical logistic regression modeling demonstrated that when controlling for individual-level risk factors (i.e. maternal age and chronic disease states), Appalachian residency was not a significant predictor of SMM. Similar to previous results, individual-level predictors and MSA-level economic security were significant predictors of SMM (see Chapter 2).

Discussion

Results from this study demonstrate the well-documented challenges surrounding the socioeconomic landscape of Appalachia. Although the region is home to diverse subpopulations and local economies, Appalachia is characterized by rural geography and widespread economic distress.[7] In particular, Central Appalachia, which encompasses areas of Kentucky, Tennessee, and West Virginia, is home to predominantly rural communities facing especially severe rates of unemployment and poverty.[33]

Findings contrast with prior studies, which document higher rates of chronic illnesses among Appalachian women of child-bearing age compared to their non-Appalachian counterparts.[7, 74] These discrepancies may be attributable to limitations within the MarketScan Research Database. The nature of the MarketScan Research Database excludes some of the most vulnerable Appalachian women from analyses; namely, rural Appalachian women living in communities outside the geographic borders of MSAs. Rural

status is associated with SMM,[99] and rural communities face a disproportionate burden of chronic disease and all-cause mortality.[19] Health disparities in rural communities are largely driven by rural counties with high poverty rates.[19] Current analyses are limited in their ability to examine rural women within Appalachia, as well as the interplay between economic security and rurality within Appalachian communities.

Despite such limitations, findings from these analyses have implications for Appalachian communities. Economic security was found to be a significant predictor of SMM nationally. Programs to address economic insecurity (i.e. high rates of unemployment and poverty) may have implications for maternal pregnancy outcomes, as well as a wide range of other health disparities.

APPENDIX 2. QUALITATIVE INTERVIEW QUESTION GUIDE

Interview Guide: Patients

Demographic Questions

1. How old are you?
2. To what address would you like us to send a $30 check?
3. With which race(s) do you identify? (If needed, list: White, Black/African American, etc.)
    a. Choose not to respond
    b. White
    c. Black or African American
    d. Asian
    e. American Indian or Alaska Native
    f. Other
4. Do you identify as Hispanic?
    a. Yes
    b. No
5. What is the highest degree in school you have completed?
    a. Less than high school
    b. High school
    c. Some college
    d. College/Associate degree
    e. More than college
    f. Other
6. How many times had you been pregnant? (Including the pregnancy with severe complications)
7. How many biological children do you have?
    a. (If multiple pregnancies): In how many pregnancies did you have severe complications?
8. Thinking back to the [first/second] time you got really sick during pregnancy…
    a. How old were you?
    b. In which county did you live?
        i. How long had you lived there?
    c. What was your marital status?
        i. Single
        ii. Married
        iii. Widowed
        iv. Divorced
        v. Separated
        vi. Other
    d. Did you have health insurance?
        i. Yes
        ii. No
            1. If yes, do you remember what kind?

a. Private
b. Medicaid
c. Medicare
d. Self-pay/None
e. Other
f. Unknown

9. [Repeat question 8 if participant experienced multiple pregnancies with severe morbidity]

Semi-Structured Questions

10. Please begin by telling me about the pregnancy which resulted in severe complications. What do you remember from your experience?
11. How did you decide when and where to seek prenatal care (at the beginning of your pregnancy)?
12. How did you decide when and where to seek medical care when complications began to arise during your pregnancy?
13. Did you experience any problems or barriers when trying to seek care for your pregnancy?
    a. If yes: Tell me about what made it hard to get care.
    b. If no: That's great to hear. A lot of women we talk to say that there were things that made it hard for them to get the care they needed. Why do you think you didn't have these problems? Why do you think they did?
14. How did your friends and family respond to your hospitalization?
    a. Probe: Did you feel supported during this time?
15. What additional resources (if any) do you wish you had during pregnancy?
    a. Some women also mention they would've liked more support from friends or family. How do you feel about that?
    b. (If multiple children): Some women say they would've liked to have more help with childcare. How do you feel about that?
    c. What resources did you find particularly important/helpful that you did have?
16. What did your doctor or other provider tell you about your health problems during your pregnancy? That is, how did the doctor explain your health issue?
    a. Did that explanation make sense to you? Why or why not?
17. I'd like you to think about "rural culture." When you think about "rural culture," what's the first thing that comes to mind?
    a. How do you think a woman's culture could affect the healthcare she receives during pregnancy and following birth?
        i. Probe: How could a woman's culture affect her decision-making about healthcare?
18. How do you think your rural Appalachian culture affected the healthcare you received during pregnancy or after you gave birth?
19. Now, I'd like you to think about the word "discrimination." When you think about "discrimination," what's the first thing that comes to mind?

    a. How do you think discrimination could affect the healthcare a woman receives during pregnancy and following birth?
        i. Probe: How could discrimination affect a woman's decision-making about healthcare?
20. Can you describe any experiences with discrimination you faced in healthcare during pregnancy or after you gave birth?
21. Before we end our discussion, do you have any last thoughts on your experience during pregnancy or following birth that you would like to share?

Interview Guide: Providers

Demographic Questions:

1. How old are you?
2. With which race(s) do you identify? (If needed, list: White, Black/African American, etc.)
    a. Choose not to respond
    b. White
    c. Black or African American
    d. Asian
    e. American Indian or Alaska Native
    f. Other
3. Do you identify as Hispanic?
    a. Yes
    b. No
4. What type of professional training have you completed?
    a. MD
    b. DO
    c. APRN/Nurse Midwife
    d. PA
    e. Other
5. What is your area of specialty?
    a. Obstetrics and gynecology
    b. Family medicine
    c. Emergency medicine
    d. Other
6. In which county do you practice?
7. For how many years have you practiced?
8. In what setting do you practice?
    a. Outpatient clinic
    b. Hospital
    c. Emergency department
9. How many prenatal visits do you see per week?
10. How many deliveries do you do per week?
11. By your best guess, how often do you have a delivery that involves a severe maternal morbidity?

Semi-Structured Questions

12. Can you please tell me why you think women in your area are more likely to experience severe maternal morbidity than other women in Kentucky or the nation?
    a. Our studies have found that rural women in your community are much more likely than urban Kentucky women to receive a blood transfusion when they deliver. Why do you think this may be?
        i. Probe: Transfusion may reflect pre-delivery factors, such as nutritional anemias or anemia of pregnancy, or at-delivery factors, such as hemorrhages. Which factors most commonly lead to transfusions in your patient population?
        ii. Probe: I'm curious if you might employ more or less conservative treatment for some women based on social factors. By social factors, I mean things like their ability to attend follow-up appointments and their home life. How do social factors affect your clinical decision-making?
            1. Probe: I'm also curious if women's education plays a role. By education, I mean both formal education and overall health literacy. How does education affect your decision-making?
13. How do pregnant and postpartum women in your patient population seek care for a complication?
14. How do you decide where to transport a pregnant woman who needs urgent obstetric care?
15. How much do you know about the availability of obstetric care resources and the provision of specialized services at different locations? For instance, when you decide to transfer a patient, do you know whether or not there is an OB/GYN or MFM specialist readily available, or an upper-level NICU? (Explain if needed: I'm curious if providers are able to match patients to the appropriate acuity of care. There have been many efforts in trauma and neonatal care to streamline transfers so as to not waste time during medical crises – severe traumas go to a level 1/2 trauma center, early preterm babies go to a level 3/4 NICU. No such standards exist in obstetric emergencies – so how do providers use their knowledge of available resources to make clinical decisions?)
16. Without providing patient-identifying information, please tell me about a time a woman experienced a severe maternal morbidity or died from pregnancy-related causes.
    a. In these sorts of critical situations, how do you decide what to do? What factors influence your course of action?
17. Can you tell me about any policies (either national, state, or hospital-based) that have influenced maternal pregnancy outcomes?
    a. Probe: Some hospitals have implemented checklists for the management of obstetric emergencies – they have tried to standardize the management of postpartum hemorrhages or preeclampsia. (You may have heard of "bundles.") Why might this sort of policy be helpful (or unhelpful)?

    b. Probe: I haven't heard you mention any policies on substance use in pregnancy. In your experience, how have practices surrounding substance use in pregnancy affect maternal outcomes?
    c. Probe: I haven't heard you mention women's health insurance. In your experience, how has women's insurance coverage impact their pregnancy outcomes?
        i. (Probe if providers only discuss insurance during pregnancy): How might post-partum insurance coverage affect pregnancy outcomes? How about insurance prior to conception?
18. I'd like you to think about "rural culture." When you think about "rural culture," what's the first thing that comes to mind?
    a. How do you think a woman's culture could affect the healthcare she receives during pregnancy and following birth?
        i. Probe: How could a woman's culture affect her decision-making about healthcare?
19. Now, I'd like you to think about the word "discrimination." When you think about "discrimination," what's the first thing that comes to mind?
    a. How do you think discrimination could affect the healthcare a woman receives during pregnancy and following birth?
        i. Probe: How could discrimination affect a woman's decision-making about healthcare?
20. How do you think severe morbidity and mortality among pregnant women in your patient population could be alleviated?
    a. Probe: Sometimes when we discuss strategies, it's helpful to consider at whom the strategy is targeted. Are there patient-level strategies you think might be helpful that target things like patient education or women's decision-making?
    b. Probe: What about provider-level strategies? Are they ways we might better equip rural providers to manage critically ill obstetric patients?
    c. Probe: What about policy-level strategies? (Reference earlier discussion of policy from Q15 if necessary).
21. We know COVID-19 has complicated care delivery, and created new risk for both patients and healthcare providers. How has COVID-19 affected your ability to provide care to pregnant and post-partum women?
22. Do you think COVID-19 is affecting maternal health in your patient population?
23. Before we end our discussion, do you have any last thoughts that you would like to share about this topic?

Interview Guide: Emergency Medical Technicians

Demographic Questions

1. How old are you?
2. To what address would you like us to send a $30 check?
3. What is your gender?
    a. Male
    b. Female

    c. Non-binary
    d. Other
4. With which race(s) do you identify? (If needed, list: White, Black/African American, etc.)
    a. Choose not to respond
    b. White
    c. Black or African American
    d. Asian
    e. American Indian or Alaska Native
    f. Other
5. Do you identify as Hispanic?
    a. Yes
    b. No
6. In which county do you practice?
7. For how many years have you practiced as an EMT?
8. How many pregnant women do you provide services for per month?

Semi-Structured Questions

9. Can you please tell me why you think women in your area are more likely to experience severe maternal morbidity than other women in Kentucky or the nation?
10. Without providing patient-identifying information, please tell me about the sequence of events in an emergency that involved a pregnant woman.
    a. What was your role in her care?
    b. How do your responsibilities fit in with the responsibilities of other healthcare providers in these emergency situations?
11. When you are called during an obstetric emergency, who is in charge of deciding where women are transported?
12. We know that many more women in this region need emergency care during their pregnancies than in other places. Can you please tell me why you think this is?
    a. What could be done to reduce the impact of these complications?
    b. Could EMTs play a role? If so, how?
13. I'd like you to think about "rural culture." When you think about "rural culture," what's the first thing that comes to mind?
    a. How do you think a woman's culture could affect the healthcare she receives during pregnancy and following birth?
        i. Probe: How could a woman's culture affect her decision-making about healthcare?
14. Now, I'd like you to think about the word "discrimination." When you think about "discrimination," what's the first thing that comes to mind?
    a. How do you think discrimination could affect the healthcare a woman receives during pregnancy and following birth?
        i. Probe: How could discrimination affect a woman's decision-making about healthcare?

15. How much information is available to you concerning the availability of obstetric care at different locations? For instance, when you transfer a patient, do you know that there is a doctor available who specializes in pregnancy?
    a. Probe: Sometimes when we discuss strategies, it's helpful to consider at whom the strategy is targeted. Are there strategies that target patients that might be helpful? These could focus on things like patient education or women's decision-making.
    b. Probe: What about strategies that target EMTs? Are they ways we might better equip you and your colleagues to manage critically ill obstetric patients?
16. We know COVID-19 has complicated care delivery, especially for first responders like yourself. How has COVID-19 affected your ability to provide emergency care, especially for pregnant women or new mothers?
17. Do you think COVID-19 is affecting maternal health in the population you serve?
18. Before we end our discussion, do you have any last thoughts that you would like to share related to EMT's care of pregnant women?

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VITA

Anna Christine Hansen was born in Chapel Hill, North Carolina in 1993. She graduated from Pomona College in Claremont, California in 2015, where she majored in biology and minored in anthropology. She matriculated into the MD/PhD program at the University of Kentucky in 2016. She has published in the *Journal of Rural Health*, *Women's Health Reports*, and *Health Equity*, among other academic journals. In 2020, she was awarded a Ruth L. Kirschstein Individual Predoctoral Fellowship from the National Institute of Child Health and Human Development. Her other awards include the 2021 John A. O'Donnell Award in Sociology from the University of Kentucky, the 2020 Clifford C. Clogg Scholarship in Sociology from the Inter-University Consortium for Political and Social Research, and the Wimberly C. Royster Graduate Excellence Award from the University of Kentucky College of Arts and Sciences.