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Measures of women's access to care in maternal and child mortality surveillance systems: evidence and implementation

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Abstract

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Maternal and child deaths are tragic events that continue to occur at unacceptably high rates worldwide. Two surveillance systems, the Child Health and Mortality Prevention Surveillance (CHAMPS) Network and Maternal Mortality Review Committees (MMRCs), aim to identify specific causes of death; however, they do not include measures of social determinants of population health. The purpose of this dissertation is to advance the use of theory-informed measures of a globally-relevant social determinant - women's barriers and access to healthcare - in routine maternal and child mortality surveillance systems.

In **Aim 1**, we evaluated the acceptability of a social autopsy tool using key informant interviews and focus group discussions to qualitatively analyze its acceptability and explore its validity at the CHAMPS Sierra Leone site. We found the social autopsy was generally acceptable to the community since it is linked to efforts to improve children's health. Participants referenced positive perceptions about health facilities, suggesting possible social desirability bias in responses.

In **Aim 2**, we estimated the effect of delays in accessing prenatal or obstetric care on neonatal mortality using a social autopsy questionnaire in a case-control study. Logistic regressions were used to estimate the effect. Analyzing 53 neonatal deaths and 140 neonatal controls, each additional barrier was mildly associated with neonatal death (OR=1.38, CI=0.92, 2.07), particularly delays that occurred at the facility (OR=19.15, CI=3.90, 94.19) and each additional barrier in women who did not report medical complications (OR =2.06, CI=1.17, 3.65).

Finally, in **Aim 3**, we evaluated differences between a pregnancy-related mortality ratio (operationalized as deaths per live-births) and a pregnancy-related mortality rate (operationalized as deaths per women of reproductive age) using data from MMRCs in nine U.S. states. For 322 pregnancy-related deaths, associations of county-level contraception need and other contextual exposures were similar or slightly stronger using live births as the denominator, except the estimate among black women for percent black population (RR=0.52 vs. 1.96). Additionally, the black-white disparity was stronger when using women of reproductive age as the denominator (RR=3.13 vs. 2.45).

In conclusion, measures of women's access to reproductive care are important to include in maternal and child mortality surveillance systems. Future work should focus on optimizing these measures and linking social factors to specific causes of death.

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Table of Contents

List of Figures

List of Tables

CHAPTER 1: INTRODUCTION

Burden of Maternal and Child Deaths

The death of a mother or a child is a tragic, often preventable loss for individual families and for communities. These events are often considered indicators of the strength of a health system, since they may suggest the failure to have sufficient services in place to offer preventive care or to respond to emergencies.[1,2] Maternal and child mortality remain unacceptably high around the world, with an estimated 275 thousand maternal deaths and 5.8 million deaths of children under five years old occurring in 2015.[3,4]

Sierra Leone

The majority of this burden is concentrated in the developing world, including sub-Saharan Africa. In Sierra Leone, the under-five mortality rate is 120 deaths per 1,000 live births.[3] Primary causes of deaths are neonatal preterm birth, respiratory infections, and diarrheal diseases.[5,6] Although under-five deaths have decreased recently, neonatal deaths (0-27 days) have not decreased as quickly, and now constitute 45% of under-five deaths.[5] Women's access to prenatal care and delivery with a skilled birth attendant are associated with these neonatal deaths, although variation in study results suggests that quality of care and local context are important factors in the relationship between access to care and mortality.[7,8]

Evidence on causes of death and contributing factors is limited in developing countries such as Sierra Leone. Measuring cause of death and factors that contribute to specific deaths is difficult due to limited civil vital registration systems, lack of mortality review processes, and poor healthcare infrastructure. Many of the statistics available come from data sources with limitations (such as verbal autopsy) or from small-scale research studies.[9]

United States

Despite a lower absolute burden, countries in the developed world continue to struggle with maternal and child deaths. In the United States, the maternal mortality ratio is 17.3 deaths per 100,000 live births, and it has been increasing in recent decades counter to the decreases seen in most other countries. Additionally, there are large racial disparities in maternal deaths; non-Hispanic black women have a maternal mortality rate three to four times as high as non-Hispanic white women, making it one of the maternal/child health outcomes with the most extreme inequality.[10] Primary causes of maternal mortality in the United States are maternal cardiovascular conditions and other medical conditions.

Data on maternal deaths come from National Center for Health Statistics (from birth and death records) and Pregnancy Mortality Surveillance System (PMSS), which also draws data from death records provided by states. However, these systems have difficulty accurately determining whether a death is causally related to the pregnancy or not, if the death would have been preventable, and specific recommendations to prevent future deaths.[11]

Enhanced surveillance systems

These issues with determining causes of death and contributing factors, found in very different settings, have led to the creation of enhanced surveillance systems for monitoring maternal and child deaths. Surveillance systems are critical for monitoring the burden of maternal and child mortality, trends over time, and disparities within and between countries. Per the guidelines issued by the Centers for Disease Control and Prevention (CDC), public health surveillance is defined as 'the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health. Data disseminated by a public health surveillance system can be used for immediate public health action, program planning and evaluation, and formulating research hypotheses.'[12]

These enhanced surveillance systems gather in-depth information on individual cases to determine a cause of death, contributing factors, and in some cases to determine preventability. Two such systems that are currently operating are the Child Health and Mortality Prevention Surveillance (CHAMPS) Network and the Maternal Mortality Review Committee (MMRC) system.

CHAMPS in Sierra Leone

While decreasing over the past several decades, under-five mortality continues to be unacceptably high globally, with an estimated 5.9 million children under five years of age dying in 2015.[3] Despite persistently high under-5 mortality rates, especially in many low income countries, deaths are usually not captured by surveillance systems and the causes of death are incompletely described. When cause of death is investigated, a standard WHO verbal autopsy (post-mortem questionnaire) administered to family members of the deceased is often used.[9] The verbal autopsy questionnaire collects data predominantly related to symptoms experienced by the child through interviews with the parent. This tool has a limited ability to capture clinically precise details related to cause of death or information on the broader social context that might relate to important contributors to fatal outcomes from illness. Few questions on the standard verbal autopsy relate to social issues such as access to care, socioeconomic status, and care-seeking or illness-preventing behaviors.[13]

The Child Health and Mortality Prevention Surveillance (CHAMPS) Network is a long-term Gates-funded surveillance program designed to collect information on under-five mortality and to identify causes of death in these children in seven countries. Minimally Invasive Tissue Sampling (MITS), verbal autopsies, and clinical information will provide information for determining cause of death. The goal of CHAMPS is to better describe specific pathogens and conditions that contribute to death and identify more accurate measures of mortality with the goal of yielding evidence-based strategies and targeted interventions to prevent childhood mortality.

One of the CHAMPS sites is located in Bombali Shebora and Siari chiefdoms, Sierra Leone, where reducing child mortality is a leading health priority during the recovery period following the Ebola epidemic. UNICEF estimated that Sierra Leone had an under-five mortality rate of 120 per 1,000 live births in 2015, which puts it among the highest under-five mortality rates in the world.[3] Reducing maternal and child mortality has been identified as a priority in the Sierra Leone President's post-Ebola recovery plan. Major known causes of mortality in this population include respiratory infections, diarrheal diseases, and complications of birth and prematurity.[6] Barriers to access to care are also acknowledged as contributing to disease processes, but they are not explicitly considered as causes of death in the broad classification system typically used. Before social determinants can be integrated into a causal framework for understanding child deaths, the social factors that are specific to this context must be measured and the association with child mortality assessed.

MMRC's in United States

Data on maternal mortality in the United States comes from three primary sources: National Center for Health Statistics (NCHS), Pregnancy Mortality Surveillance System (PMSS), and state and local maternal mortality review committees. NCHS uses death certificates, which indicate whether a woman was pregnant or within 42 days of the end of the pregnancy at the time of her death, to define maternal deaths. However, due to the limitations of death certificate and ICD-10 based classification of maternal deaths, a complementary national system called PMSS has been developed. States identify possible pregnancy-associated deaths (with time period defined as while pregnant or within one year postpartum) through a 'pregnancy checkbox' on the death certificate, key words on the death certificate, or by linking death certificates to birth and fetal death certificates in the year prior to death. Medical epidemiologists at the CDC then review these deaths to determine which are *causally* linked to pregnancy

(pregnancy-related) and assign a cause of death code. NCHS and PMSS provide crucial population-level data and trends over time, but provide limited information on contributing factors and preventability of deaths.[11,14]

In contrast, state- and urban-based maternal mortality review committees (MMRC's) have been proposed as one way to get more in-depth information on specific and actionable underlying causes and contributors to maternal deaths, as well as aggregating deaths for surveillance purposes. While some MMRC's are long-standing, there has been a recent effort to provide technical support and standardize the process through the Maternal Mortality Review Information Application (MMRIA) system. As of July 2017, MMRC's have been functioning in approximately 27 states and 1 city for more than a year, with an additional 21 review committees in planning stages or functioning for less than a year; a team at CDC has engaged with over 40 of these jurisdictions to provide technical support for a standardized process for reviewing maternal deaths.[15] These committees are typically composed of a diverse group of clinicians and other key stakeholders, including physicians specializing in obstetrics and gynecology, cardiology, pathology, and anesthesiology; nurses and nurse practitioners; social workers or other community workers; and others, depending on the state's need and availability.[11,14] The MMRIA system prompts review committees to answer six questions for each death reviewed as outputs: 1) Was the death pregnancy-related? 2) What was the cause of death? 3) Was the death preventable? 4) What were the critical contributing factors to the death? 5) What are the recommendations and actions that address those contributing factors? 6) What is the anticipated impact of those actions if implemented?[14]

Social determinants – theory

Ecosocial Theory

Despite this enhanced data collection, these systems are still missing important information on social determinants of health, which have been linked theoretically and empirically to maternal and child outcomes. Concepts in social epidemiology such as Nancy Krieger's ecosocial theory provide a theoretical grounding for understanding how social influences affect health.[16]

Ecosocial theory posits that social dimensions act across multiple levels and are embodied in biological outcomes, and that explicating these pathways of embodiment can increase accountability and lead to specific avenues for intervention.[16] It provides a comprehensive theory for describing mechanisms by which societal level exposures may be 'embodied', or become physical realities for individuals, thus impacting their health. It theorizes contextual causes exist, while going a step further to think in both directions beyond this. It asks specifically how societal causes lead to individual differences in disease, and it pushes researchers to consider how these societal causes come to exist in the first place.

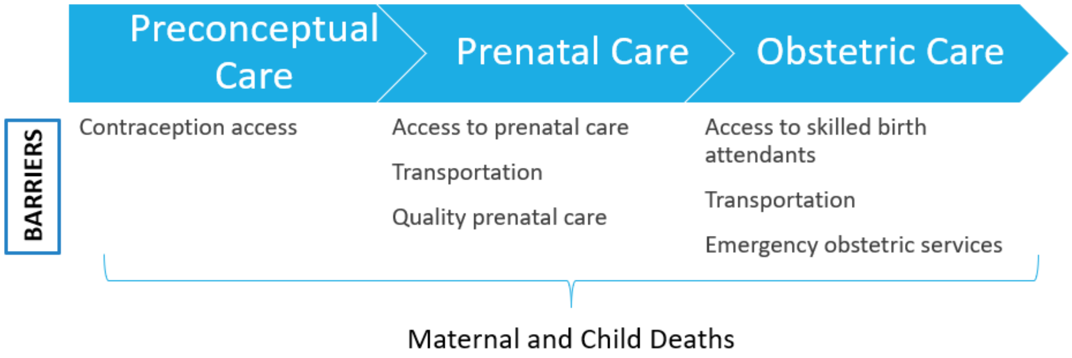
Two key tenants of this theory are: pathways to embodiment, or the process by which social forces are incorporated into a person's physical health over his or her lifetime; and agency and accountability, or an explicit focus on who can affect change at different levels on the health of individuals and populations. The lack of integration of social and biological data in our public health systems limits our ability to assess pathways to embodiment (a missed opportunity since these systems often contain rich individual biological and clinical data) and to correctly determine accountability for these deaths (which limits our conclusions and recommendations to the level where we have information). Krieger argues that the inclusion of theory- and evidence-based socio-spatial measures into public health surveillance systems can facilitate accountability at a policy level for population causes of disease, and can help public health information match current theory and evidence on societal sources of disease causation.[16,17]

Social determinants of health is a broad category that encompasses a number of different dimensions or ways that context become embodied, such as socioeconomic status, race/ethnicity, physical/built environment, and access to care. In this dissertation, I will focus on women's access to reproductive healthcare since it is important for maternal and child outcomes across different settings and provides a target for early prevention.

Women's access to care

Women's reproductive care occurs across a continuum of time in relation to a pregnancy; preconceptual, prenatal, and obstetric care are all important components for health reproduction. Each of these time points has various dimensions that constitute quality care, and barriers in accessing care at any of these points can lead to poor outcomes for the mother and child. Figure 1-1 shows a schematic of this idea, with examples of specific dimensions that influence quality care at each time point.

Figure 1-1. Continuum of women's access to care



While ecosocial theory provides a theoretical basis for thinking about how access to care is embodied in health outcomes, the Three Delays Model provides an organizational framework for measuring specific aspects of access to care. First used by Thaddeus and Maine to describe maternal mortality in Haiti, it groups delays into three main types: Type 1 is a delay in *deciding to access care*; Type 2 is a delay in *reaching a healthcare facility* once the decision has been made; and Type 3 is a delay in *receiving appropriate and adequate care* once arriving at the facility.[18]

With respect to this continuum, I will focus on prenatal and obstetric care and its associations with neonatal deaths in Aims 1 and 2 using CHAMPS data in Sierra Leone; and I will consider preconceptual care in Aim 3, specifically access to contraception, and its associations with maternal deaths in the United States.

Social determinants – evidence

Three Delays Model

Since its development, the Three Delays Model has been used often as a foundation for understanding how access to care can affect maternal and neonatal outcomes.[19–24] A number of qualitative studies have further characterized context-specific delays in accessing care. Results from these studies demonstrate the range of ways barriers are discussed and understood, and the variability across contexts.[19–21]

A recent meta-analysis of 17 studies that employed the three delays framework found that the most common barrier reported was a type 3 delay (38.7%), followed by a type 1 delay (28.0%).[25] However, these numbers cover wide variability in individual study findings; one study on neonatal deaths in Ethiopia found that 81% reported type 1 delays versus 16% reported type 3 delays, whereas a study on maternal deaths in Malawi determined that 40% of women experienced type 1 delays versus 97% experienced type 3 delays.[22,23] This variability has clear implications for policy makers and other stakeholders seeking to prevent as many deaths as possible using limited resources.

In addition to providing a model for describing barriers, the Three Delays Model also helps break the concept of lack of access to care into actionable steps and to identify priority areas for prevention. For example, one study on maternal use of health services in Ethiopia found that women's lack of trust in the health system and lack of knowledge about danger signs and symptoms were major factors in a delay in deciding to seek care, and that a lack of supplies was a major delay in receiving care once at the facility.

Thus, they recommended that the clinics focus on education and community outreach and that health policy makers focus on logistics at the clinics.[19]

While the Three Delays Model was developed primarily for use in resource-limited settings, the concepts can be applied to access to healthcare in the United States as well. Meyer and colleagues applied this framework to delays in accessing prenatal care in rural and peri-urban areas of Georgia. Using qualitative methods, they identified a number of barriers to women accessing timely prenatal care: awareness of pregnancy and stigma contributed to delays in deciding to get care; choosing a doctor and receiving insurance coverage contributed to delays in accessing care; and continuity of care and communication contributed to delays in receiving adequate care.[26] This demonstrates that even in a context where access to care should be high, there can be delays in accessing care that follow similar time patterns to those in developing countries.

Prenatal and obstetric care and neonatal deaths

In general, research on access to health care and child mortality in Sub-Saharan Africa has had mixed results. A pair of studies looking at variability in country-level measures of access to healthcare found that up to 75% of the between-country differences in under-five mortality could be explained by access to health care, and that it was the more significant than social, economic, and environmental factors in explaining Africa’s high rates of under-five mortality.[27,28] On the other hand, a systematic review highlighted the abundance of research on traditional measures of access such as distance and cost, but also the discrepancies in associations uncovered between these measures and child mortality.[7] They suggest that recent focus on non-traditional measures of access to care, such as social support systems, available time, and female autonomy might provide more convincing results of the importance of access to care, and cite several recent studies that found associations.

Evidence on the effect of antenatal care (ANC) visits and skilled birth attendant (SBA) during delivery may be particularly relevant for neonatal mortality. One study examining the association between antenatal care and child health outcomes in 69 low and middle income countries using Demographic Health Survey (DHS) data found that attending at least one ANC visit was associated with a 1.04% reduction in the absolute risk of having a neonatal death compared to not attending ANC.[29] A meta-analysis found that attending ANC was associated with a 34% reduction in neonatal deaths compared to those who did not attend ANC, although many of these individual studies were cross-sectional and the results of the meta-analysis are not controlled for potential confounders.[8] The weak or absent effects reported in some studies could be due in part to variability in antenatal care quality; while 51% of women attended at least one ANC visit in one study, only 5% of those had the recommended 8 interventions performed.[30]

Studies of the presence of skilled birth attendant and place of delivery are similarly mixed, although most studies find some degree of association between presence of a skilled birth attendant and neonatal mortality. A meta-analysis by Chinkhumba and colleagues found that delivery at home was associated with significantly higher perinatal mortality compared to delivering at a facility (OR: 1.21); however, as the authors note, there was substantial heterogeneity in the estimates from individual studies.[31] An analysis of DHS data from nine countries found births at home without a skilled birth attendant had higher early neonatal mortality than those at a facility, even after adjusting for reported complications at birth (OR: 1.3).[32] Amouzou et al. found that presence of an SBA was not associated with neonatal mortality on the first day of life, but was associated with death on days 2-27.[33]

Some studies suggest that the relationship between access to care, socioeconomic factors, and mortality might be complex and dependent on the local context. A recent analysis of data from the Demographic Health Survey showed that access to free delivery services provided in three countries (Sierra Leone, Senegal, and Ghana) resulted in an increase in deliveries with professional attendants. Although this difference was not different by wealth index, it was different by education level.[34] A study of distance to facilities with Emergency Obstetric and Neonatal Care (EmONC) in Ethiopia found that distance to a facility with comprehensive EmONC was associated with early neonatal mortality, and that this was not due to socioeconomic factors. Instead, they found that socioeconomic differences in early neonatal mortality were explained largely by household wealth as opposed to distance.[35]

Modeling estimates demonstrate the large number of lives that could be saved every year if these interventions were implemented, highlighting the vast number of pregnancies and children at risk despite weak associations. The Every Newborn Action Plan foucses on ending preventable neonatal deaths and stillbirths through investing in effective interventions across the life cycle and improving quality of maternal and newborn care, among other objectives.[36] Bhutta et al., as part of the Every Newborn Study Group, drew on previous systematic reviews and individual studies and determined that if known antenatal interventions were implemented worldwide, 43,000 neonatal lives would be saved by 2025, and if known interventions for obstetric care were implemented, 790,000 neonatal lives would be saved in the same time period.[37] They suggest that 25% of neonatal deaths could be avoided with skilled birth care alone, with up to 40% avoided with emergency obstetric care available.

Preconceptual care and maternal deaths

Access to contraception and preconceptual care are thought to be associated with maternal mortality through direct effects of increasing pregnancies and indirect effects on maternal mortality once pregnant. Indirect effects imply that pregnancies that are unwanted or mistimed have higher adverse outcomes than wanted and properly timed pregnancies; for example, evidence shows that shorter inter-pregnancy intervals are associated with the negative clinical outcomes of premature rupture of membranes and placenta previa.[38] Modeling estimates typically take these indirect effects into account by estimating change in maternal mortality ratio for unintended pregnancies, which may be higher than that for intended pregnancies due to differential risk profiles and abortion risks.[39] Stover and Ross estimated these indirect effects, calculating that 75% of births in countries with low contraception use had a risk factor due to age or parity compared to 35% of births in countries with high contraception use.[40] They estimated that decreases in the total fertility rate from 1990 to 2005 (which they attribute primarily to increased contraception use) resulted in 1.2 million avoided maternal deaths.

Since data linking access to family planning to observed maternal mortality is lacking, researchers have looked to other maternal indicators. Preconceptual health indicators also differ by race, age, and socioeconomic status, suggesting these could be drivers of racial disparities in pregnancy outcomes.[41] Studies on family planning and other maternal outcomes have been mixed; one study found longer distance to a family planning facility to be associated with lower teenage pregnancy rates, and not associated with unintended pregnancy.[42]

Past implementation of social determinants in surveillance systems

Because of the theoretical link between access to care and maternal and child mortality, studies such as those previously discussed as well as others have attempted to estimate effects of access to care in observed data. A number of studies have used surveillance systems that already exist or newly-developed data tools to examine this link empirically. In the global health literature, a Social Autopsy tool has been developed to complement the Verbal Autopsy tool used in many settings to gather data on these factors. In the United States, data from nationally representative surveys are often used to estimate or model effects of access to care on mortality or other maternal indicators.

Development of Social Autopsy tool

Due to data limitations on access to and attitudes about care, socioeconomic factors, and contextual variables from the verbal autopsy, a complementary social autopsy has been proposed.[13,43,44] This can be administered as a stand-alone survey or integrated with the verbal autopsy into a single questionnaire.[13] The purpose of this tool is to collect additional data on social factors that potentially contributed to a death, particularly for maternal, perinatal, and child deaths. A better understanding of household level social factors associated with child mortality can help reduce disparities in health outcomes.

In the first published systematic review on the subject of social autopsy in 2011, Kalter and colleagues define social autopsy as "consist[ing] of questions on modifiable social, cultural, and health system factors that contribute to the same deaths investigated by verbal autopsy".[13] Kalter goes on to trace the origins of the social autopsy tool to maternal death reviews, which he claims had an earlier focus on community and health systems factors in contributing to deaths. Eventually, with the development of the Three Delays Model and the pathway to Survival Model, research investigating social and behavioral factors surrounding child deaths intensified. This review discusses steps taken to refine the early social autopsy tools used, culminating in the Child Health Epidemiology Reference Group (CHERG) creating an updated social autopsy format in 2009. Presenting next steps for the social autopsy field, Kalter discusses how the social autopsy tool may need to be adapted further, due to its length, and the need for validation.

Also in 2011, another attempt to develop a standardized tool to collect information on social factors and access to healthcare for child deaths was published by a group from the International Network for the Demographic Evaluation of Populations and their Health (INDEPTH). Based on several previous surveys, a group of experts formed a Social Autopsy Working Group and developed a Social Autopsy tool that was implemented in four different Health Demographic Surveillance Sites (HDSS).[45]

Since 2011, the number of social autopsy studies has steadily increased. Whereas the review article by Kalter discussed 14 articles on child deaths and 8 on maternal deaths that examined care seeking processes (of which only a few were termed social autopsy tools), a more recent review by Moyer and colleagues in 2017 identified 16 articles published between 2005 and 2016 that explicitly used a social autopsy tool.[13,43] Again, Moyer and colleagues found that lack of standardization and validation of social autopsy tools to be a challenge. Across the 16 studies reviewed, five different social autopsy tools were used; and of the 16 studies, four did not describe the tool in sufficient detail to determine its source or type. Moyer reported that the majority of studies cited the CHERG social autopsy tool, the WHO Verbal Autopsy tool, and the INDEPTH Network's combined verbal/social autopsy tool.[46,47] One study has assessed the acceptability of a 'social autopsy' tool in Bangladesh; however, the social autopsy used in this setting consisted of a community discussion following a death, and thus may not be applicable to the individual interview used in the majority of the social autopsy literature.[48]

Findings from Social Autopsy studies

As summarized in the reviews by Kalter and Moyer, findings from previous social autopsy studies have shown that there is a high recognition of severe signs and symptoms by caregivers among fatally ill children, but that this is not always followed by appropriate careseeking. Most of the studies used the Three Delays Model and/or the Pathway to Survival Model to analyze the results. There were high levels of delaying seeking care or seeking care with non-formal providers in the studies reviewed. Particularly for neonates, the reported rates of seeking care at any point in time for the fatal illness ranged from 28% to 76%. Cost was the most often-cited barrier to seeking care, with distance, lack of transportation, and perceived low quality of care also frequently cited. Many of these early studies did not report results on delays encountered after reaching the healthcare facility; of those that did, type three delays were most common in one of the four studies, and second most common in the remaining three.[24,45,49]

Since 2016, several additional social autopsy studies have been published. One study in Nigeria determined the primary delays to be cost, lack of transportation, and distance, with a median time of two days between onset of severe symptoms and care seeking.[50] Two other studies of neonates in Ethiopia and India found that type one delays were most common, followed by type three delays; however, both studies collected information on healthcare seeking in fewer than 40 neonates.[22,51] Studies of maternal deaths in India also found that type one delays were the most common, with one study identifying almost half of women trying a home remedy or traditional healer before seeking formal healthcare. When type three delays were present, they focused on delays in initiating treatment, absence of doctors, and referral to hospitals with appropriate equipment.[52,53]

While most social autopsy studies are case-only assessments of deaths, there are a few notable exceptions. Kalter et al. performed a case-control study of neonatal deaths and stillbirths in the West Bank and Gaza Strip; however, they only compared medical complications and place of delivery between cases and controls, not care-seeking constraints or quality of care variables. In cases, they identified Israeli checkpoints, deficiencies in medical management, and facilities not equipped to handle obstetric emergencies as constraints on care seeking and quality factors.[54] More recently, in Rwanda, Gupta and colleagues performed a matched case-control analysis of under-five deaths using nearest neighbors as controls. They identified that being born at home (OR: 2.0), reporting not having a family member to accompany them as a barrier (OR: 1.6) and perceiving medical services as moderate to poor (OR: 1.5) were associated with neonatal deaths.[55] Finally, Snavely et al. carried out a prospective case-control study of febrile in-patients in Tanzania. They determined that for pediatric patients, each additional delay was associated with an increased risk of death (OR: 1.28). For specific types of delay, type one delays were not associated with death; certain measures for types two and three were, although many estimates were imprecise due to the low number of cases (18 pediatric deaths).[56]

Data sources to assess social factors and maternal mortality

In the United States where civil registration is more comprehensive compared to countries in the developing world, questions of access to care and maternal and child health outcomes are often addressed through nationally-representative surveys or large datasets. Many studies of maternal mortality at the state or national level rely on National Vital Statistics System (NVSS) mortality data from the National Center for Health Statistics.[57–60] To link these births to sociodemographic or behavioral covariates, studies such as these use information from birth/death certificate data or link to state-level variables from sources such as American Community Survey (ACS), Area Health Resource File (AHRF), or Behavioral Risk Factor Surveillance System (BRFSS).

The Pregnancy Risk Assessment Monitoring System (PRAMS) is a surveillance system of maternal behaviors, attitudes, and experiences around the time of pregnancy, representative of women delivering a live birth, providing an additional source of information on maternal social factors.[61] However, most studies examine maternal indicators other than mortality as outcomes, such as hypertension, gestational weight gain, or teenage pregnancy.[42,62,63]

Recently, as state- and urban-based maternal mortality review committees (MMRC's) have been revived, a few studies have emerged analyzing results in a single state or city. Briller and colleagues examined maternal deaths due to cardiovascular causes in Illinois from 2002-2011, using specific etiology and preventability information from the MMRC to estimate that 28% of the cardiac deaths were potentially preventable.[64] A similar study by Main et al. for California pregnancy-related deaths from 2002-2005 determined that 41% had a good or strong chance of being preventable, and they found that the most commonly identified contributing factor to death was delayed response of the healthcare provider to warning signs.[65]

Findings on access to healthcare and maternal mortality in the US

In general, access to care has been found to be associated with maternal mortality or maternal risk factors in the United States. One study looked at expansion of Medicaid to cover prenatal care and its effect on immigrant women in Oregon, using Medicaid claims data. They determined that expansion did not affect severe maternal morbidity or mortality, but was associated with increased diagnosis of complications during pregnancy such as gestational diabetes.[66] Other studies have also found prenatal care to be associated with maternal mortality.[60]

Access to care may also underlie racial differences in maternal mortality. One study found that non-Hispanic black women had similar rates of preeclampsia/eclampsia, postpartum hemorrhage, placenta previa, and placental abruption compared to non-Hispanic white women, but had higher case fatality rates.[67] There are numerous factors that could account for this discrepancy, but access to quality healthcare is one potential reason black women have a higher fatality rate from the same conditions as white women.[67,68] Additionally, black women present later, on average, for prenatal care and have lower rates of surgical intervention for obstetric hemorrhage compared to white women, again suggesting possible differences in care.[68,69]

Rural areas, in particular, in the United States may have reduced access to prenatal and obstetric care. In 2004, 45% of rural counties had no hospital obstetric services, and an additional 9% lost hospital obstetric services between 2004-2014.[70] In an analysis of the same data, Kozhimannil and colleagues found that the proportion of births occurring outside of a hospital or at a hospital without obstetric services increased by 0.7 and 3.1 percentage points, respectively, in counties that were not adjacent to urban areas and lost hospital obstetric services.[71] They also found that there was a 4.4 percent increase in women having fewer than 10 prenatal visits in counties not adjacent to urban areas that lost obstetric services.

Access to care and rurality in the United States are also tied to racial disparities. When looking at counties with no hospital obstetric services, the percentage of non-Hispanic black women was associated with a ten-fold higher likelihood of not having services versus having services that continued through 2014.[70] Platner et al. looked at pregnancy-related deaths in Georgia between 2010-2012 and found that while the pregnancy-related mortality did not differ between rural, non-rural, and metro Atlanta, the black-white disparity was greater in non-rural and metro Atlanta compared to rural areas.[72]

Gap

Because access to care is theoretically and empirically linked to maternal and child well-being, there is a need to measure these factors in mortality surveillance systems. In developing countries, previous research has relied on an emerging tool outside of routine surveillance systems and has not focused on estimating causal effects of access to care using this tool. In the United States, studies have used established surveillance systems with limited information on deaths and have used a definition of population at risk that may obscure some associations of access to care and mortality. Measuring the relative contribution of women's access to care in ongoing enhanced mortality surveillance systems could give a more complete picture of the cultural, political, and temporal context in which these deaths are occurring. It could aid in estimation of causal effects and prioritization of policies and interventions, particularly in resource-constrained settings. Additionally, women's access to care may influence observed disparities in maternal and child deaths by race, socioeconomic status, and education, giving better insight into mechanisms for the disparities. Incorporation of rigorous measures into routine data collection would allow us to conduct targeted interventions to improve maternal well-being and to prevent maternal and child deaths.

Goals and Aims

The overarching goal of my dissertation is to advance the use of theory-informed measures of social determinants of maternal and child mortality in routine surveillance systems. In this dissertation, I will incorporate multileveled measures into two population-based enhanced surveillance systems of child and maternal mortality (CHAMPS, MMRCs) in order to quantify the contribution of women's barriers and facilitators of health care as determinants of death. In Sierra Leone I will assess the acceptability of an emerging tool, the Social Autopsy, as a complement to the current Verbal Autopsy in CHAMPS. Then I will use the Social Autopsy in a pilot case-control study to estimate the contribution of delays in maternal care seeking to neonatal mortality. In the U.S. I will link geospatial measures of reproductive health services to geocoded maternal death data from a CDC MMRC database to estimate the association between family planning need and area-based pregnancy-related mortality rates, comparing these associations between different populations at risk. Completing this research in two different populations and surveillance systems demonstrates that this approach of incorporating multileveled pathways to embodiment of health and illness into locally-relevant surveillance systems can provide valuable data for monitoring the population health in that region. Specifically, the following aims will be addressed:

Aim 1: Evaluate the acceptability of collecting social measures using a social autopsy tool to community members in the CHAMPS catchment area in Sierra Leone. Additionally, explore perceptions of the validity of these measures in this population.

Aim 2: Estimate the effect of barriers to women's access to prenatal and obstetric care for neonatal mortality in Sierra Leone using data from a pilot case-control study. Demographic Health Survey data will then be used to assess the impact of selection bias on these results.

Aim 3: Evaluate differences between a pregnancy-related mortality ratio (operationalized as deaths per live-births) and a pregnancy-related mortality rate (operationalized as deaths per women of reproductive age) at a county level in the United States, characterizing differences by type of county (urban/rural, percent poverty). Assess the association of women in need of contraception with this pregnancy-related mortality ratio and pregnancy-related mortality rate.

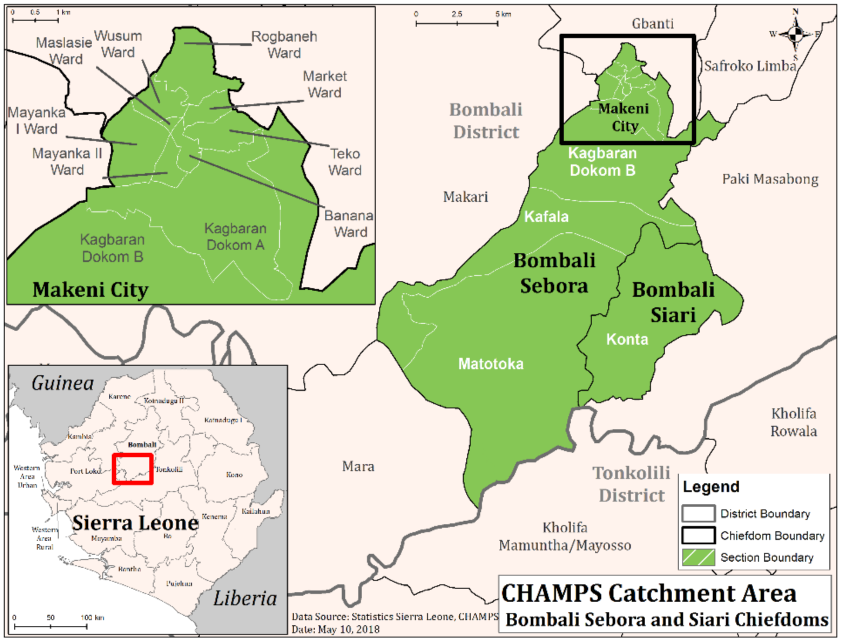
CHAPTER 2: DATA SOURCES

CHAMPS

Study Population

The research for Aims 1 and 2 was conducted at the CHAMPS site in Sierra Leone (see Figure 2-1 for map). This site is located in the Bombali Sebora and Siari chiefdoms, with a catchment population of 161,383 (125,970 in Makeni City and 36,413 in rural areas). The estimated under-five mortality rate for Sierra Leone is 120/1,000 live births, and there are approximately 5,500 live births per year in this catchment area. Data collection occurred between October-November 2017 for Aim 1, and from March-November 2018 for Aim 2.

Figure 2-1. Map of the CHAMPS catchment area in Sierra Leone



Data Source: Statistics Sierra Leone, CHAMPS
Date: May 10, 2018

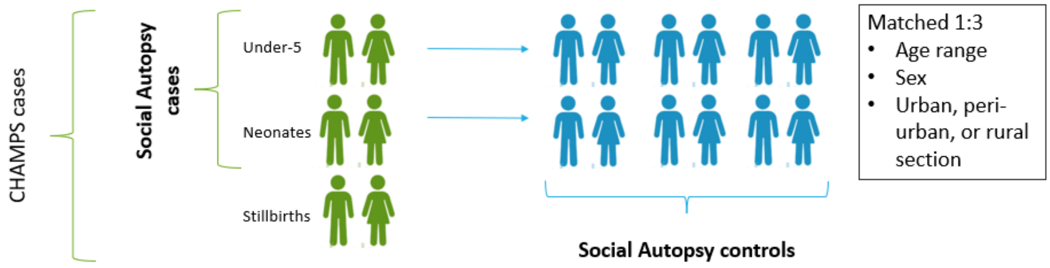
(Map produced by Mary Claire Worrell, CDC/CHAMPS)

Social Autopsy Study Design

Both aims focus on the pilot implementation of a social autopsy (SA) tool. The social autopsy tool is a structured questionnaire administered to the primary caregiver after a death. It collects information on socioeconomic status, household factors, and access to care that may have contributed to a death. It is primarily used as a supplement to a verbal autopsy (VA) tool, which collects information on medical signs and symptoms to determine cause of death. There are several versions of the social autopsy tool currently in use, and there is no consensus on a standard version to be used. The version used in this research was adapted from the INDEPTH Network's combined VA/SA tool.

In addition to implementing a SA tool in routine CHAMPS Sierra Leone data collection, time-limited data were gathered on control (living) children to compare to CHAMPS cases. CHAMPS cases consist of under-five deaths and stillbirths that have resided in the catchment area for at least four months. For the purposes of the case-control study, only non-stillbirths were included as cases to be matched with controls due to the difficulty of identifying controls for stillbirths (see Figure 2-2). For data collection on controls, the social autopsy tool was modified for children who were still living to a 'Social Factors Questionnaire'. These modifications consisted primarily of slight wording changes to reference a living rather than a deceased child. Controls were matched to cases in a 3:1 ratio on age range, sex, and general location. Specifics of the case-control study will be discussed further under Aim 2 methods.

Figure 2-2. Case-control study design for social autopsy study



MMRC’s

Study Population

The third aim will include pregnancy-related deaths from the Maternal Mortality Review Information Application (MMRIA) for complete years in the numerator; live births from NCHS or reproductive-aged women from ACS at the county level in the denominator; and county-level exposure data from Guttmacher Institute and ACS. MMRIA is a data collection platform developed by CDC to be used by Maternal Mortality Review Committees (MMRC’s) for entering, reviewing, and aggregating data used during the review process in a more comprehensive and standardized way. The goals of MMRIA are to facilitate consistent data collection between jurisdictions and to enhance quality of indicators that can lead to action. Thus, MMRIA provides an opportunity to collect standardized information on social factors detrimental to maternal health that can lead to concrete systematic recommendations.[73,74] MMRIA enables the linkage of maternal deaths to contextual (i.e. county-level) exposures through matching the geocoded address to publicly available sociodemographic, healthcare, and other structural indicators measured at a county level.

MMRIA currently aims to capture all pregnancy-associated deaths in participating states. Pregnancy-associated deaths are defined as any death of a woman that occurs while pregnant or within a year after the end of the pregnancy, regardless of location or duration of the pregnancy (see Table 2-1).[14] Within pregnancy-associated deaths, cases are divided into those determined to be related to pregnancy, (i.e. the pregnancy or its management contributed to the death); pregnancy associated but not related deaths, (i.e. deaths that occur during the time period but are not due to the pregnancy); and pregnancy associated but unable to determine relatedness, (i.e. there is not enough information to determine if a causal link with pregnancy exists).[14] For deaths entered into MMRIA prior to the 2017 report, approximately 27% of all deaths were determined to be pregnancy-related.

For this analysis, data come from nine states that had complete years of data available totaling 322 pregnancy-related deaths for analysis. Table 2-2 gives information on the states, years, and pregnancy-related deaths.

Table 2-1. Definitions of types of deaths recorded in MMRIA and numbers

Pregnancy associated deaths	Pregnancy-related	Death of a woman while pregnant or within one year after the termination of the pregnancy, and her *pregnancy contributed* to the cause of death
	Not pregnancy-related	Death of a woman while pregnant or within one year after the termination of the pregnancy, but the *pregnancy did not contribute* to the death
	Unable to determine if related	Death of a woman while pregnant or within one year after the termination of the pregnancy, but *unable to determine* if the pregnancy was related to the death
Not pregnancy associated (false positive)		The death was not a pregnant woman or occur within one year of the termination of the pregnancy

Table 2-2. Pregnancy-related deaths in analysis, by year and state

State	**Year**	**# Pregnancy-related deaths**
Arizona	2016	5
Delaware	2009	4
	2010	1
	2011	1
	2012	0
	2013	1
	2014	3
	2015	1
	2016	1
Georgia	2012	23
	2013	30
Hawaii	2015	3
Illinois	2015	12
Mississippi	2016	8
North Carolina	2015	18
Ohio	2008	16
	2009	34
	2010	22
	2011	25
	2012	20
	2013	16

	2014	15
	2015	22
	2016	16
Utah	2015	13
	2016	12
Total		**322**

Denominator information for women of reproductive age come from county-level measures from the American Community Survey (ACS), which is a rolling survey conducted on a continuous basis by the Census Bureau to provide more timely estimates than the decennial census. As such, the study population for the denominator includes all reproductive-aged women in the United States as ascertained by the ACS, using their sampling and estimation techniques.[75] An estimated 3 million addresses are selected every year, resulting in approximately 2 million completed interviews that are intended to be nationally representative. To provide reliable estimates due to the smaller number of completed interviews, metrics for smaller geographic areas are combined into 5-year estimates. For this project, the 5-year estimates are used for variables from ACS to allow estimation down to the county level.[75] Denominator information for live birth data comes from the National Vital Statistics System, part of the National Center for Health Statistics. This system collects a standardized form of demographic and health information on all live births that occur in the US.[76]

Exposures come from two publicly available sources, the Guttmacher Institute and ACS. Percent of the population in poverty, percent non-Hispanic black, and percent rural come from 5-year ACS data, as described above. Family planning need and number of Title X clinics come from Guttmacher Institute data, which is an institute committed to research on reproductive and sexual health. As part of that mission, they publish a periodic report on contraceptive need in the United States. This report uses data from the Census Bureau, American Community Survey, and National Survey of Family Growth to derive estimates of women in need of contraceptive services and supplies, and women in need of publicly funded contraceptive services and supplies, which are then modelled at a county level.[77] Women are defined as ‘in need of contraceptive services and supplies’ if they are sexually active, not known to be sterile, and are not pregnant or trying to get pregnant.[77] Title X clinics are defined as sites that receive funding from the Title X federal funding program for family planning. Data on these clinics were obtained from the Office of Population Affairs (OPA), the Health Resources and Services Administration (HRSA), Indian Health Service (HIS), and individual state agencies or individual organizations.[78] Percent poverty, percent non-Hispanic black, and percent rural were defined as the number people in each of these categories divided by the total population.

CHAPTER 3: Acceptability and validity of a social autopsy tool as part of under-five and stillbirth mortality surveillance at a Child Health and Mortality Prevention Surveillance Network site in Sierra Leone

Abstract:

Purpose: In areas with poor vital registration, a verbal autopsy is often administered to the caregiver to assess causes of under-five deaths. Because it collects limited information on social and healthcare access factors, a complementary social autopsy has been proposed. Despite increased use of this social autopsy tool, little research has explored its acceptability and validity. The objective of this study is to describe the acceptability of a social autopsy tool at a Child Health and Mortality Prevention Surveillance (CHAMPS) site in Sierra Leone and to explore the validity of this tool.

Methods: For the acceptability sub-study, four key informant interviews and four focus group discussions were conducted. These interviews were transcribed, coded, and a thematic analysis was performed. The validation sub-study occurred in a subset of participants of a larger social autopsy case-control study. Responses from the adapted social autopsy interview were compared to responses from an in-depth qualitative interview with the same respondent, and a kappa statistic was calculated for concordance.

Results: The idea of a social autopsy is generally acceptable to the community since it is linked to efforts to improve children's health. A non-judgmental attitude and appropriate approach to the family are essential for this acceptance. Participants referenced positive perceptions about health facilities, suggesting possible social desirability bias in responses. When comparing individual answers in the pilot validation study, answers for participants were generally consistent, although there may be underreporting of barriers to care on the structured questionnaire.

Discussion: This is the first systematic evaluation of the acceptability and validity of a social autopsy tool. In general, social autopsy is a concept with generally high acceptability that collected valid data on types of care received. Future work should focus on mitigating social desirability bias and optimizing questions on barriers to care.

Introduction

Background

Under-five mortality remains unacceptably high globally, with 5.8 million children dying in 2015.[5] This is a problem particularly in developing countries where the rates can be as high as 130/1,000 live births.[5] A number of social and environmental factors are associated with these deaths, including antenatal care attendance, relative wealth, exposure to cooking smoke, and getting care early for a child's illness, among others.[7,79–81] Access to care can help explain the large disparities in under-five mortality between countries, and increasing access to interventions during ANC (e.g. tetanus vaccination) and during birth (e.g. skilled attendance with access to emergency obstetric care) are primary targets for intervention.[27,82,83] While studies of access to care using traditional metrics such as cost and distance have shown mixed results, broader measures such as social support systems and available time of caregivers may also be important components of access.[7] Others have suggested that poor quality of care could explain weak associations of access to care and mortality by attenuating the beneficial impact of accessing care.[84] In order to quantify the impact of timely access to quality care on under-five mortality, measures of access need to be assessed in mortality surveillance systems.[13]

Mortality Surveillance – CHAMPS Network

In countries with constrained healthcare and vital registration systems, the Verbal Autopsy is often used to gather information on cause of death.[9,85] Verbal Autopsy is a standardized questionnaire conducted with the family of the deceased to obtain information on cause of death.[9] However, it collects limited information on socioeconomic, household, and healthcare access factors that may contribute to a death. A complementary tool called a social autopsy has been proposed to address this gap.[13,43] A recent pilot implementation of a social autopsy tool in the setting of a larger research project, the Child Health and Mortality Prevention Surveillance (CHAMPS) Network, has provided the opportunity to collect data on the acceptability and validity of a social autopsy tool in this setting.

The CHAMPS Network is a long-term Gates-funded surveillance program with sites in seven countries in sub-Saharan Africa and South Asia, designed to collect information on under-five mortality and stillbirths and to identify causes of death in these children (*Salzberg, 2019, submitted for publication*). Minimally Invasive Tissue Sampling (MITS), verbal autopsies, and clinical information are gathered to provide information for determining cause of death. The goal of CHAMPS is to better describe specific pathogens and conditions that contribute to death and to identify more accurate measures of mortality in order to yield evidence-based strategies and targeted interventions to prevent childhood mortality.

Social Autopsy gaps

In recent years, the increase in use of social autopsy in research projects has been documented by two published review articles and several original research articles.[13,24,43,48,51,55,86–89] These studies have demonstrated the presence of delays in accessing health care for children who have died, as well as the variation by context.

Despite the increased use of the social autopsy, there is a lack of information on the process and potential barriers for implementing a social autopsy tool. The most recent review article published by Moyer et al in 2017 discussed the lack of a standardized tool as a gap in the social autopsy literature, with five different social autopsy tools used across sixteen studies. Only one published study has evaluated the community acceptance of a social autopsy tool; however, the social autopsy tool evaluated was a community-based discussion around the death, which is fundamentally different from the caregiver interview used in most social autopsy studies.[48] In order to move towards a standardized tool and to optimize implementation, more data are needed on the operationalization of a caregiver social autopsy tool.

Research Question

While a social autopsy is currently used to collect potentially important data on contributing factors to deaths, there is little data on the acceptability of this questionnaire for parents of a child who has died and a lack of consensus on the structure of this interview. The objective of this study is to describe the acceptability of a social autopsy tool and to explore barriers to the validity of responses on healthcare seeking behavior in the setting the CHAMPS Sierra Leone site.

Methods

We conducted a qualitative study and a pilot validation study to address the acceptability and validity of a social autopsy tool in the setting of the CHAMPS Sierra Leone site. Qualitative methods were used to assess the acceptability, including participants' understanding and perceptions of the concept of a social autopsy tool and any context-specific facilitators or barriers. Building on results from the acceptability sub-study, a pilot validation sub-study was also conducted to explore the validity and potential for social desirability bias of an adapted social autopsy tool for living children.

CHAMPS Site

One of seven initial CHAMPS sites is located in Bombali Shebora and Siari chiefdoms, Sierra Leone, where reducing child mortality is a leading health priority during the recovery period following the Ebola epidemic. UNICEF estimated that Sierra Leone had an under-five mortality rate of 120 deaths per 1,000 live births in 2015, which puts it among the highest under-five mortality rates in the world.[6]

Major known causes of mortality in this population include respiratory infections, diarrheal diseases, and complications of birth and prematurity.[6]

To assess the feasibility of adding a social autopsy tool to routine CHAMPS data collection, a pilot study of social autopsy use was implemented at the CHAMPS Sierra Leone site. This study was timed to coincide with the initiation of verbal autopsy data collection at this site, so the social autopsy was integrated into the data collection procedures. Sub-studies were conducted to 1) assess the acceptability of a social autopsy tool in this setting, and 2) explore the validity of healthcare seeking questions.

Social Autopsy Tool

The social autopsy tool was developed from an INDEPTH Verbal Autopsy / Social Autopsy questionnaire. First, the social autopsy components that were not included in the Verbal Autopsy were consolidated, and the questionnaire was reviewed with local partners. Next, the social autopsy was translated into Krio and Themne by trained translators. It was then back-translated by an independent translator. The translated tool was then tested on focus groups of community members to assess understanding and develop a finalized version.

The social autopsy tool collected information in several domains: socioeconomic factors (eg parental education, relative wealth); household factors (eg water source and treatment, sanitation); and barriers and delays in accessing healthcare (for the mother during pregnancy and for the child's fatal illness). The social autopsy interviews were conducted following the verbal autopsy, typically within a week after the death occurred.

Assess Acceptability of Social Autopsy

Design

To assess the acceptability of a social autopsy interview in the context of the CHAMPS Sierra Leone site, key informant interviews (KIIs) and focus group discussions (FGDs) were carried out in two CHAMPS pilot communities in Bombali Shebora. KIIs were conducted to explore perceptions and insights on community reactions to a social autopsy tool from leaders and influential members of the communities. These were complemented by FGDs designed to elicit understandings from a variety of community members. Interview guides with questions and probes were developed for each type of data collection, and they were refined and translated into Krio and Themne through discussion with the CHAMPS Socio-behavioral science team. The guides were then pilot tested for understanding of respondents.

Study Population

The team recruited participants from two peri-urban pilot communities in the Bombali Shebora chiefdom of Sierra Leone. The CHAMPS Socio-behavioral science team had been engaging with and conducting formative research in these communities for approximately eight months before the initiation of this data collection. Participants were recruited through a combination of lists of community members previously generated by CHAMPS and snowball sampling from these initial contacts. To maximize discussion in FGDs, participants were recruited to be homogenous within a given group with respect to gender and broad age group. We recruited participants for four FGDs – two all-male and two all-female, each with one group 18-24 year olds and one group 25+ year olds. Additionally, KII’s were conducted with a pastor, an imam, a headman, and a chair lady. Sociodemographic information on the participants is displayed in Table 1 in the results section below.

Data Collection

A team of two interviewers conducted all KIIs and FGDs. Both had bachelor or masters level education and experience with quantitative and qualitative data collection. They were instructed on ethics and oriented to the CHAMPS project and Social Autopsy Project. Both were native speakers of Krio, and one was a native speaker of Themne. For each interview, one team member was the primary interviewer and the other was responsible for taking written notes. Informed consent was obtained for all KII and FGD participants before beginning the interview, and permission was requested and granted to audio record all interviews. Ethical approval for this study was obtained as part of the larger social autopsy study from the Sierra Leone Ethics and Scientific Review Committee and the Emory University Institutional Review Board.

Transcription, Coding, and Analysis

After completion of data collection, the interview team transcribed all interviews verbatim from the audio recording. They transcribed and translated the interviews simultaneously, writing transcripts directly in English. A separate team performed quality control by listening to the audio recordings and checking the transcripts. Following transcription, the primary analyst reviewed the transcripts to become familiar with the data and to address any questions with the interview team.

Codes were developed in an iterative process to include inductive and deductive themes. First, a list of inductive codes was developed *a priori* by the primary analyst based on the research questions. Next, a thorough reading of the data led to additional codes developed from themes in the data. These deductive codes were combined with the inductive codes for a codebook to be used by a team of two analysts. Each analyst used the codebook to code one interview and intercoder reliability was calculated. The analysts compared the coded transcript and discussed any inconsistencies, updating the codebook in the process. After review and discussion of the codes, another transcription was coded. At this point, the codebook was finalized, and each analyst coded each interview separately.

After coding the data, a thematic analysis was conducted to understand broad themes in the data. Individual codes, groups of codes, and overlaps of codes were reviewed and described. This was an iterative process, with additional overlaps and comparisons made as new questions and themes emerged.

Explore validity of Healthcare Questions

Design

To explore the validity of healthcare seeking questions on the social autopsy tool, we conducted a sub-study within a larger social autopsy case-control study. The CHAMPS social autopsy case-control study used additional time-limited data collection on living children for comparison to CHAMPS cases. Inclusion criteria for these controls were a living child under five years old who resided in the catchment area and was matched to a case on age, sex, and residential location. The social autopsy questionnaire was adapted for an interview about living children, and questions on healthcare seeking behaviors were only asked of illnesses experienced in the previous two weeks. The full methodology and results from this case-control study will be published in a separate article.

Study Population

The study population consisted of all control participants enrolled in the social autopsy case-control for a six week period in June-July 2018 who consented to both interviews, yielding 17 neonatal and 14 child controls. For this study, participants were not limited to the pilot areas from the acceptability study, but instead were from the entire catchment area. Selection points were generated in a geographically random manner within urban areas and rural communities, and the house closest to the random point was approached for eligibility. Eligible households were ones where a resident child matched a recent CHAMPS-enrolled case on age, sex, and general location (urban, peri-urban, or rural section).

Data Collection

For a subset of control participants (n=31), two interviews were conducted: the adapted social autopsy questionnaire and an in-depth qualitative interview focused on recent healthcare seeking behaviors. For control participants, the adapted social autopsy refers to healthcare seeking for recent illness; the neonatal questionnaire additionally asks about careseeking during pregnancy and labor and delivery. The interviews were conducted approximately one week apart and the order in which they were given was randomized. For all interviews, the respondent was the same for the adapted social autopsy and the in-depth qualitative interview. Ethical approval for this study was obtained as an amendment to the approvals for the social autopsy study from the Sierra Leone Ethics and Scientific Review Committee and the Emory University Institutional Review Board.

Analysis

After collection of the data, key variables were compared between the two interviews for each participant. Two researchers reviewed each in-depth interview transcript to extract a pre-determined set of variables related to healthcare seeking behaviors and barriers. After separately extracting these variables from each interview, the datasets were compared between researchers and any discrepancies discussed and resolved. The corresponding variables were then identified from the adapted social autopsy, and the values were compared for each participant to determine concordance between the two interviews. The types of concordance considered were full or partial concordance (both answers identical or almost identical, in the case of open-ended answers), answer/no answer discordance (information present in one interview but not in the other), and answer discordance (different answer between the two interviews).

Results

Assessing Acceptability of Social Autopsy

The average age of FGD participants was 20 and 22 for the younger groups, and 33 and 42 for the older groups. In contrast, the KII participants were older on average. Participants were predominantly Themne-speaking with a range of educations and occupations (see Table 3-1).

Table 3-1. Demographics of participants in qualitative acceptability study

	KII	**FGD**				
	KII (n=4)	**Combined (n=27)**	**F, 18-24 (n=7)**	**M, 18-24 (n=7)**	**F, 25+ (n=6)**	**M, 25+ (n=7)**
Age (yrs)	53	29.0	20	22	33	41.6
Avg # kids (n)	8.5	3.2	1.7	1.3	4.5	5.6
Age of kids (%)						
< 5 yo	14.7	47.1	75	100	25.9	41.0
> 5 yo	85.3	52.9	25	0	74.1	59.0
Education (%)						
None	0	48.1	14.3	57.1	83.3	42.9
Primary	50	18.5	42.9	0	0	28.6
Secondary	25	29.6	42.9	42.9	0	28.6
Higher	25	3.7	0	0	16.7	0
Occupation (%)						
Farmer	25	70.4	42.9	57.1	83.3	100
Trader	25	3.7	14.3	0	0	0
Student	0	22.2	42.9	42.9	0	0
Other	50	3.7	0	0	16.7	0
Primary Language (%)						
Themne	75	100	100	100	100	100
Fullah	25	0	0	0	0	0

Acceptability

In general, participants indicated that the social autopsy would be an accepted survey since it was related to children's health. An overarching theme to many responses was the importance of children's health. They suggested that the perceived benefits of the CHAMPS project in general, and of the social autopsy in particular, would lead community members to respond, even to sensitive questions related to household matters and healthcare.

> "…it is for our own benefits because if you left all other work and come here in our community to talk to us it means you have interest in our wellbeing (Imam; 129)"

It was also evident throughout the interviews that community members do not draw clear distinctions between research and giving advice. Many saw the primary purpose of the social autopsy questionnaire as giving advice to the community to take their children to the health facility or to clean their households. They viewed this advice favorably and felt that it was contributing to the health of their children.

> "If you tell him/her to take the child to the health facility, that parent, the parent who understands will say this man has not given me money but he has also given me money, because he has helped me. It means he has showed love to me for my child not to die (FGDm-; 141)"

Even when it was understood that a questionnaire was distinct from advice, some respondents voiced the opinion that the process of participating in a questionnaire would help people understand healthy behaviors:

> "Anyone who have an idea of what you will be telling will know that the longer you asked them question the more you will be educating them on the topic you will be discussing. So the person who is educated should not get annoy but the person who is a fool will start asking why are you asking me too much question?" (FGDm+; 211).

Timing and Length

Regarding the acceptable timing and length of a social autopsy interview, there was variability in opinions. The main issues raised in relation to timing and length were competing demands on attention and time and perceptions of the benefits of the survey. Taking time away from farming or housework was raised as a potential concern. Some suggested conducting social autopsy on a separate day from verbal autopsy, while most preferred conducting both interviews sequentially. Some respondents explicitly advised being responsive to the questionnaire participant:

> "...when they start answering your questions it will tell you whether you should continue with the other set or you should stop there and come the other day" (FGDf-; 248)

The timing may also depend on the participant's state of mind; for example, if the person is overcome with emotion, respondents recommended stopping the interview and coming back another day.

Length of time for the questionnaire was also seen as depending on perceptions of the interview and possible benefits. Again referencing the importance of children's health, a common theme was that parents would be willing to speak with you for as long as necessary since it is for the health of their children. Many linked the interview to an effort on the part of parents to not lose a child in the future.

> “And because of the pain she felt before her child die she will be willing to sit and wait for you to ask all the question, may be the way you the question you will ask her will help her to prevent her other child from dying if they get sick.” (FGDm+; 215).

Finally, the length of time a participant is willing to answer questions is also dependent on the interaction of the interviewer and participant. If the interviewer encourages the parent and is patient, the participant will feel more at ease and be willing to continue answering questions.

> “Well if you come and encourage them they will not get annoy at all. When you come you should talk to them politely, laugh with them, then you take about one hour, or forty minute, or thirty minute.” (FGDm+; 225).

Approach

A common theme discussed by participants in the qualitative study was the manner of approach used by the interviewers for a social autopsy questionnaire. Particularly in the context of asking questions about sensitive topics such as economics and the household, participants emphasized that people in the community would answer questions if they were approached “peacefully” and “politely”. They suggested the interviewers should be patient and encouraging, which will help participants calm down if they are upset and allow them time to answer the questions.

Many people specifically pointed to greetings as a way to put participants at ease. In the context of a culture where greetings are very important, greeting of the participant by the interviewer is viewed as setting the stage for the rest of the interview and for the relationship between participant and interviewer.

> “Well when you go, you meet the person in his/her house, you knock and greet good morning here, just as the same as you came to me. When you came, you greeted me good and laughed with me. So anything you ask me, I am ready to answer you (Chair lady; 49).”

After the initial greeting, the interviewer continues to set the tone of the interview by using language that is understood by the participant. In order for participants to answer the questions well, it has to be asked in a polite, simple way.

> “Well the kind ways which you come and talk to them is the way they answer you. When you come and talk to them fine, they will answer you good. (Chair lady; 25).”

In contrast, many respondents explicitly discussed the negative impacts on the interview if the interviewer was not polite or was judgmental. They talked about how participants would not react well to these negative actions, such as the interviewer raising their voice or speaking aggressively towards them.

> “… you should not condemn their own way of life, you should not look at their children with angry eye even if they looks dirty.” (FGD, male 25+, 308).

Despite this focus on not being judgmental, many respondents themselves characterized parents who did not clean their households or take their children to the health facility as ‘careless’. The tension between community perceptions and the likely reactions of participants when you ask about these topics points to the potential for social desirability bias when asking these questions.

Finally, religion plays an important role in ideas around death, which is seen as being ultimately the act of God. The influence of religion extends to perceptions about the CHAMPS study and social autopsy questionnaire. Several respondents said that referencing religion would help to ease parents' grieving and encourage them to participate.

> "There will be frustration in him/her, he/she will not feel at ease, but except you tell him/her it is God who made that to happen (Pastor, 112)"

Exploring Validity of Healthcare Questions

Perceptions about honesty/validity

The validity of the social autopsy questionnaire depends on people honestly reporting answers to questions about their household and their healthcare that may be seen as sensitive or private. One potential threat to this is social desirability bias, or answering questions based on the response the participant thinks the interviewer wants.

For a social autopsy tool, it seems that social desirability bias may be present. Participants mentioned that community members know what they should do, saying that would make them answer 'honestly'. However, this could also be a source of misclassification if respondents feel they know what the 'right' answer should be, and therefore they answer what they *should have* done rather than what they *actually* did. This response bias could go in either direction: some suggest that participants will answer more positively (e.g. that they take their children to the clinic), while some suggest they will answer more negatively (e.g. they do not have possessions when they do) because they are expecting the research program to provide benefits for them.

> "Well now they have the understanding that if you careless your child and take them to the traditional healers he/she will died immediately. You understand that is why I said so. They will answer you honestly. (Headman, 32)"
>
> "…they will answer you because they will be expecting you to help them with their problem" (FGDm+; 179)

Participants' answers also reveal that stigma may exist against not seeking care at a facility or going to a traditional healer, which could influence respondents' answers to questions on these topics.

> "Some parent are careless, even if you tell them to take their children to the hospital they will tell you I do not have money. They are just too careless, they will sit at home and pretend as if they do not have money (FGDf-; 68)".

However, despite the potential for social desirability bias, other participants were more positive about the likely honesty of people in their community, particularly when it related to the health of their children. People often mentioned that participants would be honest since the interviewers are coming with the purpose of improving health.

> "I do not think most parent will have problem talking to you because you are coming to talk to them about what will benefit them tomorrow, so they will tell you what you ask them truthfully that cause their child to die (FGDm+; 221)"

Pilot validation assessment

The potential for response bias was also explored in a pilot validation sub-study. Data were collected using a questionnaire and an in-depth interview on 31 of the control participants, of whom 17 were neonates (0-27 days) and 14 were older children (28 days – 59 months). Although a full validation study could not be performed due to the small sample size, these data can provide some insight into potential differences or similarities between the structured social autopsy/social factors questionnaire and a semi-structured interview.

Over all the variables, there were 56.2% of interview pairs that were in concordance, 27.4% recorded/non recorded pairs, and 16.3% with discordant answers (see Table 3-2). Six out of nine variables had >50% concordance for all participants. In general, questions on ANC utilization and barriers to ANC care had high concordance, while questions about barriers to labor and delivery care had lower concordance. Additionally, for some questions, there were high frequencies where information was present in one type of interview but not the other. This may point to questions where a targeted question from a questionnaire is more helpful in eliciting information, or where more open-ended questions from an in-depth interview obtain more information.

Table 3-2. Concordance of Qualitative Interview with structured Social Factors Questionnaire

Variable	% with full concordance (n=17)	% with recorded / not recorded (n=17)	% with discordance (n=17)	Cohen's Kappa	P-value
ANC, any attendance	100	0	0	1.0	0.06
ANC, number	17.6	58.8	23.5	0.13	0.71
ANC, location	70.6	5.9	23.5	-0.10	0.81
ANC, any barriers	82.4	5.9	11.8	0.60	0.05
ANC, # barriers	82.4	5.9	11.8	0.60	0.05
L&D, any barriers	58.8	17.6	23.5	0.12	0.62
L&D, # barriers	58.8	17.6	23.5	0.12	0.62
L&D, paid money for transport	11.8	58.8	29.4	-0.30	0.43
L&D, type transportation	23.5	76.5	0	1.0	0.25
Total (%)	56.2	27.4	16.3		

Review of individual controls demonstrates that the two interviews often contain similar information on barriers to healthcare. For example, for ID 2016 presented in Table 3-3, the circumstances surrounding getting ANC and labor and delivery care were similar. The participant did not mention barriers for getting ANC care, but she discussed transportation or money for transportation as a barrier for labor and delivery care. ID 1054 presents a similar pattern for an older child's illness. While there is more nuance in the qualitative interviews, the structured social factors questionnaire captures similar information. However, for other participants, the qualitative interview reveals more detailed or different answers than the structured SFQ. For ID 2011, the participant did not report any barriers in the social factors questionnaire. In contrast, in the qualitative interview, she discussed difficulties with cost at length, saying she did not attend ANC because she did not have enough money. She also reported visiting a pharmacy during her pregnancy to buy medications, something that did not come out in the structured interview. This suggests participants could be underreporting barriers in the social factors questionnaire, possibly due to social desirability bias; however, these barriers become evident during open-ended questions or on deeper discussion during the qualitative interview, when participants may experience less pressure from social desirability bias.

Table 3-3. Individual comparisons of Social Factors Questionnaire vs Qualitative Interview

ID #	Social Factors Questionnaire	Qualitative Interview
2016	Said transportation was an issue for going to deliver at hospital; said she did not pay money for transport but took a taxi. She didn't report any problems getting care before labor or once at the hospital.	For ANC did not have problems; she could afford the small 'consideration' for the nurses. For labor and delivery, when she went into labor and was ready to go to the hospital, she did not have money and her husband wasn't there. Her grandmother had to get money from people in the area to go to the hospital. On the way to the hospital, she had convulsions and lost consciousness.
2011	Reported that she did not get any ANC. Did not report any barriers for ANC, going to the hospital, or at the hospital.	Reported that at delivery she paid money, and they did not give her as many treatments as she thought she should get. She did not go to ANC care because she did not have money – by the time she got it and went, it was time for her to

		deliver. She got paracetamol (acetaminophen) at the pharmacy during the pregnancy
1054	Reported child having fever; said they went to a hospital because 'urine color is yellow'. She reported time away from normal duties as a barrier to taking the child to get healthcare. She walked to the health facility, and did not have any problems once there.	Said child has malaria recently (fever, not playing normally). She said when she takes him to the hospital, she can't sell at the market like she normally does. She says you must have money to take the child to the clinic, but does not seem to see that as a barrier necessarily.

Discussion

Overall, the idea of a Social Autopsy tool was generally accepted in the community. The community linked the social autopsy tool specifically, and CHAMPS in general, to children's health, increasing their acceptance of the process. Attitudes towards the implementation of the social autopsy tool varied, but indicated the potential for social desirability bias in responses. A pilot validation study suggested that most individuals did not have major differences between a structured questionnaire and a qualitative interview, although there appeared to be some underreporting of healthcare seeking barriers experienced.

In addition to linking the social autopsy to children's health, participants emphasized the importance of the approach of the interviewer. This indicates that thorough training of interviewers on building rapport is necessary for optimal survey administration. In relation to timing and duration, there was a variation in ideas from the community. For the implementation of the social autopsy tool, this supported flexibility in the administration of the survey: giving the participant a choice between answering social autopsy questions immediately following the verbal autopsy or taking a break between surveys.

Data from the qualitative study also suggested that there may be preconceived ideas in the community about how certain questions should be answered, whether because it is the 'correct' answer or because they will get differential benefits based on how they answer. These themes suggest that social desirability bias could be an issue in the structured questionnaire. The pilot validation study explored differences between an adapted social autopsy and an open-ended qualitative interview. It showed that for many participants, the structured questionnaire adequately captured information on social factors; however, in some cases, participants underreported barriers on the structured questionnaire compared to the open-ended interview. These results suggest that retaining open-ended questions in addition to the structured questions may be useful. Since the questions on delays in accessing care are a novel contribution of the social autopsy compared to the verbal autopsy, more work is needed to understand how participants understand and respond to these questions in the context of a recent death.

Overall, this study addressed the absence of data on community perceptions of the social autopsy tool. This is supported by the recent rapid increase in use of social autopsy recently, suggesting some amount of acceptance in the communities where these tools are being deployed. While investigating the validity of the social autopsy tool was also a goal of this study, conclusions were difficult to draw due to the limited sample size in the validation sub-study. However, results from the acceptance sub-study and preliminary results from the validation sub-study suggest that development of a standardized, validated tool should be a priority for future social autopsy research due to the possibility of response bias for sensitive topics.

Strengths and limitations

This study attempted to systematically evaluate components of the implementation of a social autopsy tool for evaluating under five mortality. A mixed methods approach strengthened the ability to triangulate evidence from qualitative results and a pilot sub-study to describe challenges and strengths in using a social autopsy tool.

A limitation of this study resides in the exploratory nature of the questions and analysis. The qualitative analysis was thematic and did not consider comparisons by subgroup. It was also limited to a small geographic area and consisted primarily of one ethnic group, and thus may not cover the full range of perspectives in the full catchment area or be generalizable to other contexts. The validation sub-study included a limited sample size, and ethical considerations for grieving parents required that it be performed on control participants (those who had not recently lost a child). This could be a limitation because patterns of responses between a structured and an open-ended interview differ between families who have recently lost a child and those who have not. Additionally, the validation study used in-depth interviews as a comparison, acknowledging that this method is not a gold standard for healthcare seeking behaviors, but might serve as a useful comparison. Future validation studies should consider comparing answers between a social autopsy on deceased children, a qualitative in-depth interview with parents, and hospital records or some other measure of clinical care. Although there may be limited sample size and important differences in the questions and the study populations answering these questions, this study could give insight into the validity of these questions in the setting of the CHAMPS study and serve as the basis for additional research.

Conclusions

This is the first systematic evaluation of the acceptability and validity of a social autopsy tool nested in a prospective surveillance system. We found that social autopsy is a concept with generally high acceptability that collected valid data on types of care received. Future work should focus on ways to mitigate social desirability bias in the questionnaire and optimize questions on barriers to care.

CHAPTER 4: Effect of delays in maternal access to healthcare on neonatal mortality in Sierra Leone: a social autopsy case-control study at a Child Health and Mortality Prevention Surveillance (CHAMPS) site

Abstract:

Purpose: While under-five mortality has been decreasing in recent decades, the decline in the neonatal mortality rate has not kept pace with that of older children. In settings with limited vital registration, a verbal autopsy questionnaire is often used to aid in cause of death determination; however, it collects limited information on access to healthcare that may have impacted the illness and death. Due to this limitation, a complementary social autopsy has been implemented in a growing number of studies. Few of these studies have focused on the effects of delays in maternal healthcare on neonatal mortality using a social autopsy questionnaire and employing a comparison group. The purpose of this study is to estimate the contribution of each type of delay in maternal health care access to subsequent neonatal mortality in a pilot social autopsy case-control design.

Methods: A case-control study was conducted at the Child Health and Mortality Prevention Surveillance (CHAMPS) Sierra Leone site. Cases were deaths of children 0-27 days old whose mothers had resided in the catchment area for at least 4 months. Controls were living children 0-27 days old, matched to cases on sex and administrative section of residence (urban, periurban, or rural). Logistic regressions were used to estimate odds ratios for barriers to care during pregnancy or labor and delivery and neonatal death, controlling for potential confounders. Stratified models examined this association by neonatal age and by self-reported medical complications. Sensitivity analyses were conducted to assess the impact of selection bias in cases and misclassification of exposure.

Results: Of 53 neonatal cases, 26.4% of the mothers experienced at least one delay during pregnancy or labor and delivery, the most common being a delay in receiving care at the facility (18.9%). In contrast,

18.6% of mothers of 140 neonatal controls experienced some barrier, of which a delay in deciding to seek care (15.0%) was most common. Experiencing any barrier was associated with a 1.68 increased odds of death (CI=0.77, 3.67), and specifically a delay in receiving care once at the facility was strongly associated with death (OR=19.15, CI=3.90, 94.19). Stratifying by early vs. late neonate, the effect of each increasing barrier was a 2.14 increased odds of death in late neonates (CI=1.05, 4.35). When stratifying by medical complications, any barrier and a delay in deciding to seek care were associated with a decreased odds of death in those who reported medical complications and an increased odds of death in those who had not experienced medical complications.

Discussion: Experiencing barriers to accessing healthcare during pregnancy or labor and delivery are associated with an increased odds of neonatal death, particularly delays experienced after arriving at the healthcare facility. There is significant heterogeneity in the prevalence of specific delays, which could have implications for public health policy and action at a local level.

Background

While under-five mortality has been decreasing in recent decades, the decline in the neonatal mortality rate has not kept pace with that of older children. From 1990 to 2015, the neonatal mortality rate decreased by 42.4% to 2.6 million deaths in 2015, compared to a 52.0% decrease for older children.[5] The first 28 days of life is a particularly dangerous period, with 45.0% of deaths in children under five years old occurring during the neonatal period and 14.5 children dying in the first 6 days out of every 1,000 live births in the world.[5] Primary causes of death in neonates include preterm birth complications, intrapartum-related events, neonatal encephalopathy, and sepsis.[5,6]

The Child Health and Mortality Prevention Surveillance (CHAMPS) Network is a long-term Gates-funded surveillance program designed to collect information on under-five mortality and to identify causes of death in these children in geographically defined sites with high under-five mortality (>50 deaths per 1000 live births) in seven countries in sub-Saharan Africa and south Asia. Unlike previous reliance on verbal autopsy alone, post-mortem minimally Invasive Tissue Sampling (MITS), verbal autopsies, and clinical maternal information will be combined to provide information for more precisely determining causes of death than has previously been possible. The goal of CHAMPS is to better characterize conditions that contribute to death and strengthen and make more precise the mortality estimates for these high mortality regions with the goal of yielding evidence-based strategies and targeted interventions to effectively prevent childhood mortality, providing a key tool for achieving Sustainable Development Goal 3.2 to end preventable deaths of children under 5 years of age by 2030.[90]

Verbal autopsy (VA), one of the tools used by the CHAMPS program, is a standardized survey with the family of the deceased used to aid in cause of death determination in areas with poor healthcare infrastructure.[9,85] The World Health Organization has worked with partners to create a standardized VA tool in 2016, with periodic updates planned.[9,91] While the verbal autopsy collects important information on clinical signs and symptoms, it does not collect detailed information on access to healthcare that may have impacted the illness and death. In the context of neonatal deaths, research has shown that women’s access to prenatal care and delivery with a skilled birth attendant are associated with neonatal deaths.[7,79,92,93] The Three Delays Model organizes delays or barriers to getting healthcare into three groups: delays in deciding to get formal healthcare (type 1 delay), delay in reaching the healthcare facility once decision has been made to seek care (type 2 delay), and delay in receiving adequate and appropriate care once arriving at the health facility (type 3 delay).[18] This framework has been implemented in numerous qualitative and quantitative studies on maternal, neonatal, and child deaths, leading to specific and nuanced information on delays for policy makers.[19] These studies have demonstrated the prevalence of delays, but also the variability in which specific, actionable barriers matter most in specific contexts. This variability points to the need to collect relevant data regarding delays or barriers to getting healthcare in routine maternal and under-five mortality surveillance.[25,43]

Due to data limitations on access to and attitudes about care, socioeconomic factors, and contextual variables from the verbal autopsy, a complementary social autopsy has been proposed.[13,43] A recent emphasis has been placed on developing and implementing a standardized questionnaire instead of the varied tools and data sources used previously in research.[13,43] A social autopsy (SA) tool can be used alone or in combination with a verbal autopsy questionnaire to identify potentially actionable contributors to mortality that are not collected in the standard WHO Verbal Autopsy tool. The purpose of this tool is to collect additional data on social factors that potentially contributed to maternal, perinatal, child, and other deaths. This can be administered as a stand-alone survey or integrated with the verbal autopsy into a single questionnaire.[13] Recent studies have implemented a combined Verbal Autopsy/Social Autopsy (VASA) tool in a number of different settings, finding that cost, distance, lack of transportation, and perceived low quality of care were frequently cited barriers.[50,86–88] Some studies have used social autopsy to link maternal and child mortality to the Three Delays model and the Pathway to Survival model, while qualitatively assessing the implementation of this tool.[13,48,94]

In addition to the standard verbal autopsy, one of the CHAMPS sites in Sierra Leone, which has one of the highest estimated child mortality rates in the world at 120 deaths per 1,000 live births, is piloting a social autopsy tool in addition to the verbal autopsy to collect additional information on social factors and access to healthcare. As part of this pilot, a case-control study was nested within CHAMPS data collection. Previous social autopsy studies have documented the presence of barriers, but have not been able to estimate their contribution to mortality by comparing barriers to a control group.[50,88,89,95] In two recent systematic reviews of the social autopsy literature and the three delays model literature, none of the studies discussed compared barriers between cases and a control group.[25,43] Since these reviews were published, a case-control study of children presenting with fever at a hospital in Tanzania did not find a significant effect of delays on mortality, although the number of cases was low and did not include children who did not present to a hospital.[56] Another case-control study examined non-traditional measures of access to healthcare (such as social support) and child mortality, but did not specifically look at delays the caregiver experienced leading up to the death.[96]

Few studies have focused on the effects of delays in maternal healthcare on neonatal mortality using a social autopsy questionnaire and employing a comparison group (with similar information collected in living children). The purpose of this study is to estimate the contribution of each type of delay in maternal health care access to subsequent neonatal mortality in a pilot social autopsy case-control design.

Methods

Study Population and Study Design

The CHAMPS Sierra Leone site catchment area consists of the Bombali Shebora and Siari chiefdoms with a population of approximately 125,970 in the urban area of Makeni City and 36,413 in rural areas. CHAMPS cases were stillbirths and children under five who died and resided in the catchment area. To be considered a resident, the child (or mother, for children under four months or stillbirths) had to have lived in the catchment area for at least four months. Participants were excluded if they did not meet these criteria or if there was a legal reason to not enroll the case. Further, for the purposes of this case-control study, cases were families with a neonatal death or stillbirth who consented to the social autopsy questionnaire. The full details of CHAMPS case enrollment can be found in a separate paper (*Salzberg, 2019, submitted for publication*). Inclusion criteria for the social autopsy sub-study cases were stillbirths and neonates who met the age and residence criteria for CHAMPS and who consented to the social autopsy survey.

Controls were neonates sampled from the community and matched to neonatal cases on sex and general location. Stillbirths were not matched to controls due to the difficulty of determining an appropriate comparison group.[97] Matching on general location occurred at the urban, peri-urban, and rural levels, which were defined based on administrative sections. Controls were identified by a process of generating random geographic points within each of these administrative sections, which served as starting selection points. Interviewers used a GPS-enabled device to visit these selection points in a random order and approached the nearest house. Inclusion criteria for controls included a living neonate, residence in the catchment area, and consenting to participate in the survey. If no eligible child lived there or there was a refusal, the next nearest house was approached until an eligible child was identified. If no child was identified within five houses then the interviewer proceeded to the next selection point.

Data collection was carried out from March to November 2018. The study protocol was approved by the Sierra Leone Ethics and Scientific Review Committee and by the Emory University Institutional Review Board. Funding for the research came from a VECD Fogarty Global Health Fellowship.

Measures

The social autopsy is a questionnaire that collects information on a wide range of factors, including socioeconomic status, household factors such as water and sanitation, and healthcare seeking behaviors. In particular, questions are based on the Three Delays Model to determine barriers to accessing healthcare during antenatal care or labor and delivery and were used as the primary exposures (Table 4-1). First, barriers were considered as a dichotomous variable for experiencing any barrier during antenatal care or labor and delivery. Next, each barrier a woman experienced was summed to create a score for the number of barriers experienced. Finally, the barriers were broken down into categories of *type of delay* based on the Three Delay model. Each of the three individual types of delay were then examined as dichotomous exposures.

Table 4-1. Definitions of healthcare seeking variables used in primary analysis

Variable	**Definition**
Any barrier	Woman reported any barrier during antenatal care or labor and delivery (yes/no)
Score	Number of barriers a woman reported during antenatal care or labor and delivery (numeric, 0-13)
Type 1 delay	Woman reported a delay in the decision to seek antenatal care or care during labor and delivery (yes/no)
Type 2 delay	Woman reported a delay in arriving at the health facility for antenatal care or labor and delivery (yes/no)
Type 3 delay	Woman reported a delay in receiving quality labor and delivery care once arriving at the facility (yes/no)

A relative wealth quintile was assessed using a shortened version of the Demographic Health Survey (DHS) relative wealth index created by Equity Tool.[98,99] Because the standard wealth quintiles produced a highly skewed categorization in our sample, probably due to the predominance of an urban population, the urban quintile cutoffs were used to categorize participants (using quintiles of the distribution of the index among urban respondents as cutpoints). Additional covariates included maternal age and maternal education level. To explore the possibility of confounding or effect modification by medical complications or danger signs during pregnancy or delivery, models were also stratified by self-reported medical complications during pregnancy or labor and delivery.

The social autopsy questionnaire was adapted from the INDEPTH combined Verbal Autopsy / Social Autopsy tool, in consultation with local partners and field staff (questionnaire available on request from author / or as supplement). Next, the form was translated into the predominant local languages of Krio and Themne, back translated, and cognitive testing was performed with community members to assess how they understood the translated questions. Finally, the form was coded for use in an Open Data Kit (ODK) platform, so the survey could be administered on a tablet. The social factors questionnaire (to be used for interviews of parents of living children) was adapted from this social autopsy tool, primarily with wording changes to reflect that the child had not died. It followed a similar process of translation and coding for electronic administration.

Primary Analysis

For the primary analysis, cases were neonatal deaths (death in the first 27 days of life), and controls were sex- and regionally-matched living newborns. Experience of delays in careseeking was the exposure of interest. Both unconditional and conditional logistic regression were considered to account for matching. However, as some researchers have asserted, analyzing matched data may not require a conditional logistic regression if strata of matching factors are not sparse, leading to multiple matched sets with the same covariates, and the matching factors are controlled for in the unconditional regression.[100,101] Based on the relatively large number of cases in the strata of confounders and the similarity of the results between conditional and unconditional models, we chose to collapse the matched sets and use an unconditional logistic regression for the primary analysis.

Confounders were included based on theoretical importance or because they were matching factors: location, sex, maternal age, maternal education, and relative wealth. Models were also stratified by infant age (early vs. late neonate) and self-reported medical complications (yes vs. no) to account for the possibility of effect modification by these variables.

Sensitivity Analyses

To assess the robustness of results to selection bias and misclassification bias, sensitivity analyses were conducted. All analyses were conducted using an exposure of whether a woman experienced any barrier. For bias analyses for selection probabilities and misclassification, unadjusted models were used (that is, the models were not adjusted for confounders in addition to adjusting for the effects of selection or misclassification bias). First, selection bias was a concern since at the early phase of CHAMPS, cases were reported primarily from deliveries that happened at a facility, and thus stillbirths or neonatal deaths that occurred following home deliveries may be missed. This possibility is supported by the higher number of facility deliveries among cases (93%) compared to controls (83%) and compared to population data from Bombali District (46%). Since women who delivered at home may have had a higher number of barriers to accessing care than those that successfully delivered at a facility, selection bias could have affected the estimates. To assess the potential impact on results, a range of selection probabilities was considered to adjust the odds ratio estimates, with DHS data used to give a lower bound on the proportion of home deliveries that would be expected.

Misclassification was also a potential problem since the exposure (barriers to healthcare) was self-reported after the outcome occurred (death of child). Therefore, there could be differential mis-reporting of the exposure by outcome. Exposure misclassification was assessed using a range of probable sensitivities and specificities, with the assumption that controls were more likely to incorrectly recall barriers experienced during ANC or delivery and thus be misclassified.

Results

Overall, there were 53 neonatal cases, 64 stillbirth cases, and 140 neonatal controls (Table 4-2). For 95% of cases and 99% of controls, the respondent to the questionnaire was the mother. Of the neonatal cases, 81.1% were early neonates (0-6 days old) versus 20.0% of neonatal controls. The majority of neonatal cases (79.2%) and controls (86.4%) lived in an urban or periurban area. The mother's average age was 24.2 (SD = 5.5) years old for neonatal cases to 26.0 (SD = 4.9) for neonatal controls. The majority of women in all three categories received at least one antenatal care visit: 98.4% of stillbirths, 98.1% of neonatal cases, and 93.6% of neonatal controls. 95.3% of stillbirths and 92.5% of neonatal cases were delivered at a healthcare facility compared to 82.9% of neonatal controls.

Table 4-2. Demographic characteristics of stillbirths, neonatal cases, and neonatal controls from a social autopsy study in Bombali Sebora chiefdom, Sierra Leone

Variable	**Stillbirths (n=64)**	**Neonatal cases (n=53)**	**Neonatal controls (n=140)**
Age (days)[1]		1 (0-4)	13.5 (7-21)
Age[2]			
0-6 days		81.1% (43)	20.0% (28)
7-27 days		17.0% (9)	78.6% (110)
28 days		1.9% (1)	1.4% (2)
Child sex[2]			
Male	54.7% (35)	52.8% (28)	52.1% (73)
Female	45.3% (29)	47.2% (25)	47.9% (67)
Mother's age[3]	25.5 (5.9)	24.2 (5.5)	26.0 (4.9)
Location[2]			
Urban/periurban		79.2% (42)	86.4% (121)
Rural		20.8% (11)	13.6% (19)
Mother's education[2]			
None	35.9% (23)	37.7% (20)	35.0% (49)
Primary	18.8% (12)	9.4% (5)	13.6% (19)
Secondary+	45.3% (29)	52.8% (28)	51.4% (72)
Married or living together[2]	90.6% (58)	77.4% (41)	67.1% (94)
Husband/partner's education[2]			
None	24.1% (14/58)[4]	19.5% (8/41)	26.6% (25/94)
Primary	13.8% (8/58)	2.4% (1/41)	4.3% (4/94)
Secondary+	55.2% (32/58)	63.4% (26/41)	59.6% (56/94)
Don't know	6.9% (4/58)	14.6% (6/41)	9.6% (9/94)
Relative wealth quintile[2]			
5th (highest)	39.1% (25)	34.0% (18)	39.3% (55)
4th	29.7% (19)	26.4% (14)	30.0% (42)
3rd	7.8% (5)	7.5% (4)	10.0% (14)
2nd	9.4% (6)	11.3% (6)	11.4% (16)
1st (lowest)	14.1% (9)	20.8% (11)	9.3% (13)
Primary occupation[2]			
Farmer	18.8% (12)	18.9% (10)	13.6% (19)
Trader	12.5% (8)	11.3% (6)	27.1% (38)
Student	4.7% (3)	5.7% (3)	3.6% (5)
Other	64.1% (41)	64.2% (34)	55.7% (78)
Received ANC[2]	98.4% (63)	98.1% (52)	93.6% (131)
# ANC visits[1]	5 (4-7)	4.5 (3.5-6)	5 (4-6)

Month ANC started[1]	4 (3-5)	4 (3-5)	4 (3-5)
# tetanus shots[1]	2 (1-2)	2 (1-2)	1 (1-2)
Slept under bednet (always or most)[2]	78.1% (50)	62.3% (33)	72.1% (101)
Delivered at a facility[2]	95.3% (61)	92.5% (49)	82.9% (116)
Delivered at home, w nurse[2]	1.6% (1)	5.7% (3)	7.9% (11)
Delivered at home, w/o nurse[2]	3.1% (2)	1.9% (4)	9.3% (13)

1. Median (inter-quartile range)
2. Percentage (number)
3. Mean (standard deviation)
4. Husband/partner's education is a percentage out of women who report being married or living together with a partner.

At least one barrier during pregnancy or labor and delivery was reported by 46.9% of stillbirths, 26.4% of neonatal cases, and 18.6% of neonatal controls (Table 4-3). Using the Three Delays Model, type 1 barriers were the most common for stillbirths and neonatal controls, while type 3 barriers were more common for neonatal cases. Each of these delays is further broken down by specific cause, showing that there were a variety of causes of the delays experienced by women. Among mothers of stillbirths, 26.6% experienced a delay in deciding to seek healthcare, with 12.5% of mothers of stillbirths referencing cost of healthcare as a concern. In contrast, while 15.0% of neonatal controls experienced a type 1 delay, the majority of these barriers were the belief that it took too much time from other duties. Low numbers of women in all categories reported delays in reaching the healthcare facility once deciding to seek healthcare (Type 2 delay). Finally, 14.2% of stillbirths and 18.9% neonatal cases reported a barrier once at the health facility, compared to 1.4% of controls. The majority of these delays were waiting a long time to be seen or being turned away, while lack of staff, lack of medication or supplies, and being treated poorly or disrespected were also mentioned in smaller numbers.

Table 4-3. Barriers to health care during pregnancy or labor and delivery for women in Bombali Sebora, Sierra Leone

Characteristic	**Stillbirths**	**Neonatal deaths**	**Neonatal controls**

	(n=64)	**(n=53)**	**(n=140)**
Any delay	46.9% (30)[1]	26.4% (14)	18.6% (26)
Delay 1 (Deciding to seek care)	26.6% (17)	9.4% (5)	15.0% (21)
Lack of recognition (thought not sick or traditional care was needed)	17.6% (3)	0	19.0% (4)
Too much time from other duties	5.9% (1)	20.0% (1)	61.9% (13)
Other person had to decide / woman was alone at home	5.9% (1)	0	9.5% (2)
Fears scolding/disrespect	5.9% (1)	0	4.8% (1)
Cost of healthcare	47.1% (8)	60.0% (3)	14.3% (3)
Too sick	5.9% (1)	20.0% (1)	0
Other	23.5% (4)	0	0
Delay 2 (Arriving at care facility)	9.4% (6)	7.5% (4)	4.3% (6)
Lack of transportation	66.7% (4)	100% (4)	100% (6)
Distance	50.0% (3)	0	0
Delay 3 (Receiving care)	14.2% (9)	18.9% (10)	1.4% (2)
Had to wait long time or turned away	66.7% (6)	70.0% (7)	100% (2)
Lack of staff	11.1% (1)	0	0
Lack of supplies/medication	0	40.0% (4)	0
Treated poorly / disrespected	33.3% (3)	20.0% (2)	0

1. All displayed as: Percent (number)

Having any barrier during pregnancy or labor and delivery was associated with a 1.68 increased odds of neonatal death after adjusting for covariates (CI: 0.77, 3.67) (Table 4-4). Likewise, summing each barrier a woman experienced into a score shows that for each additional barrier, the odds of a neonatal death increased 1.38 times (CI: 0.92, 2.07). Looking at specific types of barriers experienced, there are marked differences for each of the three types. Type 1 was associated with a slight decreased odds of death and type 2 a slight increased odds of death, although both were imprecise estimates. Type 3 barriers were the only category associated with a statistically significant increase in odds of neonatal death; experiencing a type 3 barrier increased the odds of death by 19.15 (CI: 3.90, 94.19).

Estimates were stratified by neonatal age (early vs late neonate) or self-reported medical complications during pregnancy or labor and delivery (yes vs no) since these variables may have modified the association between barriers and death. Stratifying based on neonatal age demonstrated stronger estimates for each additional delay as well as type 2 and 3 delays for late neonates as compared to early neonates. Estimates of the odds ratio were different by self-reported medical complications for any barrier, score, and type 1 delay exposures. Notably, the direction of the estimate changed based on medical complications; for example, the association between any barrier and neonatal death was 0.44 (CI = 0.10, 1.82) if a woman *reported* medical complications, while the estimated OR was 2.79 (0.99, 7.82) if a woman *did not* report medical complications.

Table 4-4. Logistic regression of barrier exposures on odds of neonatal death

Exposure	**Unadjusted OR (CI)**	**Adjusted OR (CI)**[1]	**Neonate's age**[1]		**Medical complications**[1]	
			0-6 days	**7-27 days**	**Yes**	**No**
Any barrier	1.57 (0.75, 3.31)	1.68 (0.77, 3.67)	2.25 (0.58, 8.76)	2.92 (0.71, 12.11)	0.44 (0.10, 1.82)	2.79 (0.99, 7.82)
Score	1.37 (0.93, 2.02)	1.38 (0.92, 2.07)	1.29 (0.67, 2.47)	2.14 (1.05, 4.35)	0.64 (0.32, 1.26)	2.06 (1.17, 3.65)
Type 1 delay	0.59 (0.21, 1.66)	0.62 (0.21, 1.80)	0.86 (0.17, 4.41)	0.70 (0.07, 5.49)	0.07 (0.01, 0.76)	1.54 (0.44, 5.38)
Type 2 delay	1.82 (0.49, 6.74)	1.60 (0.40, 6.40)	0.95 (0.14, 6.60)	3.02 (0.22, 27.08)	1.77 (0.28, 11.40)	1.43 (0.21, 9.80)
Type 3 delay	16.04 (3.38, 76.07)	19.15 (3.90, 94.19)	6.48 (0.72, 58.33)	55.03 (4.71, 642.4)	22.41 (2.42, 207.5)	16.14 (1.77, 147.0)

1. Adjusted for location, child sex, wealth quintile, maternal age, and maternal education.

To assess selection bias, the odds ratio was calculated assuming certain selection probabilities for cases and controls. A range of selection probabilities were considered to account for the oversampling of cases from facility deliveries. For all selection probabilities considered, the bias adjusted odds ratio is further from the null than the unadjusted estimate (Table 4-5).

Similarly for misclassification of the exposure, a range of possible sensitivities and specificities were considered. It was assumed that controls would have higher misclassification of self-reported barriers, since women with a normal pregnancy and delivery outcome may not recall barriers as easily. This analysis demonstrates that sensitivity of the self-reported exposure would have to be 0.6 among controls to bring the adjusted OR to a null value of 1.0 (Table 4-6).

Table 4-5. Selection bias analysis, adjusting for selection probabilities differential by facility deliveries

Percent with facility delivery		**Selection probability into study**				**Adjusted OR[1]**
Cases	**Controls**	**Cases, exposed**	**Cases, unexposed**	**Controls, exposed**	**Controls, unexposed**	
0.93	0.82	1	1	1	1	1.54
0.45	0.82	0.33	0.58	1	1	2.72
0.6	0.82	0.49	0.73	1	1	2.30
0.8	0.82	0.77	0.90	1	1	1.81
0.45	0.75	0.33	0.58	0.92	0.91	2.76
0.75	0.75	0.69	0.86	0.92	0.91	1.95
0.85	0.85	0.85	0.94	1.03	1.04	1.69

1. Using any barrier as the exposure; not adjusted for additional confounders

Table 4-6. Misclassification of exposure bias analysis

Case sensitivity	**Case specificity**	**Control sensitivity**	**Control specificity**	**Adjusted OR[1]**
1	1	1	1	1.54
0.9	0.95	0.7	0.95	1.24
0.8	0.95	0.7	0.95	1.47
0.9	0.95	0.6	0.95	1.00
0.8	0.9	0.5	0.9	1.08

1. Using any barrier as the exposure; not adjusted for additional confounders

Discussion

In general, experiencing an increased number of barriers during pregnancy or labor and delivery is moderately associated with an increased odds of neonatal deaths, although measurements were imprecise and there is heterogeneity by barrier type, neonatal age, and self-reported medical complications. This heterogeneity suggests that how barriers contribute to neonatal deaths may differ depending on the age of the neonate and whether there were medical complications during the pregnancy or birth. While an increase in the overall score showed an increased odds of death, there were large differences by type of delay, although these estimates were imprecise due to small sample size. Delays in deciding to get care and in arriving at the care facility were null or associated with a decreased odds of death, while a delay in receiving care once at the facility was significantly associated with an increase in death.

These results suggest that barriers to accessing appropriate and timely care during the pregnancy or delivery may contribute to neonatal deaths in this region of Sierra Leone. However, it also points to substantial heterogeneity in the degree of association depending on the type of delay experienced. Delays in deciding to seek care and in reaching a healthcare facility were either equal between cases and controls or slightly more common in controls. One possible reason for the higher number of women in the control group reporting type 1 delays, specifically that it was too much time from other duties, could be that an uneventful pregnancy and delivery seems less important to take time off from other duties, and thus they may be more likely to report this. In contrast, if a woman had a complication during pregnancy or delivery, she would be less concerned about taking time from other duties. This is supported by the differences observed when stratifying on self-reported medical complications. Among women who did not report complications, all types of barriers were associated with an increased risk of death; however, women who reported medical complications also reported much lower rates of delays in deciding to seek care. This potential difference in reporting highlights the subjective component of perceived barriers. The social autopsy tool asked about what the respondent perceived as problems rather than attempting to objectively measure delays, so results are based on the subjective, individual experience of barriers.

Delays encountered at the health facility (for example, waiting a long time or lack of medication) were significantly more common in cases compared to controls, even after adjusting for medical complications during pregnancy or labor and delivery. This could suggest that experiencing a delay could lead to worse outcomes for neonates; however, it is also possible that self-reported medical complications do not fully account for medical problems experienced during labor and delivery, and that type 3 delays would be common in any complicated delivery.

Sensitivity analyses were conducted to assess robustness of observed findings under a range of possible selection and misclassification bias scenarios. Selection bias of cases was a primary concern since case reporting occurred primarily from hospitals or health care facilities. All adjustments for these selection probabilities lead to an estimated OR further from the null, which suggests that differential selection of facility cases likely biased the results toward the null. Thus, the true association may be stronger than what we observed. The misclassification bias analysis shows that sensitivity for exposure classification among controls would have to be approximately 0.6 to bring the association of barrier score and mortality to null, assuming that controls are more likely to misremember delays encountered. This suggests that while exposure misclassification may have affected the results, misclassification would have to be substantial to bring the results to a null association.

These results reflect a theme in research around the Three Delays Model, that local context often defines which barriers are most locally relevant. For example, a study in India found that the most common delay in neonatal deaths was a delay in deciding to seek care (type 1), whereas a study of maternal deaths in Malawi found the vast majority of delays were at the health facility (type 3).[23,49] Since this study population is primarily urban, delays in deciding to get care and arriving at a health care facility may not represent important barriers to care. However, delays in care upon arrival at the health facility may be contributing risk and ultimately to neonatal deaths. This nuanced information from a social autopsy tool can provide more targeted information for public health organizations and officials in the country to target delays in women receiving appropriate care for labor and delivery. The social autopsy tool in combination with a robust cause of death surveillance system will also enable analysis of delays in healthcare by etiology.

This study was one of the first to systematically compare social autopsies from neonatal cases to similar information regarding barriers to care among neonates who have not died. In addition to this comparison, it provides valuable data on primary barriers to care among stillbirths and neonatal deaths in this region of Sierra Leone, adding to the growing literature on barriers to care and mortality. Finally, it demonstrates the feasibility and potential utility of including a social autopsy questionnaire in a larger data collection effort around child deaths.

In this study, there are several potential limitations. First, the sample size was small, resulting in imprecise estimates. Selection bias is also a concern, since case ascertainment was more robust in health care facilities than for community deaths. However, our analysis of this bias shows that these missing cases would likely yield a stronger effect estimate than that observed in our data. Another potential bias is misclassification of the exposure, which may be stronger in control participants due to lower recall of barriers with an uneventful delivery. Calculations showed that sensitivity for reporting barriers would have to be 0.6 among controls for the association to become null. While it seems unlikely that almost half of mothers of living neonates mis-remembered delays experienced, it is probable that some amount of differential misclassification occurred and biased the estimated effect away from the null. Additionally, confounding by severity of pregnancy or labor and delivery symptoms or medical conditions is a concern. Women who have symptoms during pregnancy or labor and delivery may be more likely to seek care, and also more likely to have a neonatal death occur. If barriers are a ubiquitous problem when seeking care, increased care seeking could lead to more reported barriers; thus, it would be the initial reason for care-seeking rather than the barriers that would be contributing to the death. To assess the extent to which this affected our results, we stratified by self-reported medical complications during pregnancy or labor and delivery. However, there could remain residual confounding by medical complications given that this was a non-specific variable and was self-reported (and thus subject to its own misclassification). Finally, this study assessed delays in accessing healthcare for the mother during pregnancy or labor and delivery rather than delays at the time of the neonate’s fatal illness. For older neonatal deaths, delays in seeking care for the child’s illness may have a greater impact on the death than delays surrounding the pregnancy and birth.

In conclusion, experiencing barriers to accessing healthcare during pregnancy or labor and delivery appear to be associated with an increased odds of neonatal death, particularly delays experienced after arriving at the healthcare facility. There is significant heterogeneity in the prevalence of specific delays, which could have implications for public health policy and action at a local level. Social autopsy is a tool that allows this detailed information to be gathered, and thus may be useful in ongoing surveillance of neonatal mortality.

CHAPTER 5: Association of contraception need and county-level sociodemographic factors with pregnancy-related mortality using different denominators to represent population at risk

Abstract:

Purpose: Maternal mortality continues to be unacceptably high in the United States, with stark disparities by race and socioeconomic status that could be due in part to prepregnancy health. Estimates of maternal mortality are conventionally presented as ratios of maternal deaths to live births. While live births is a proxy for women at risk of dying from pregnancy-related complications, it does not take into account drivers of the incidence of pregnancy itself, which may be more informative for studies of prepregnancy health and maternal mortality. An alternative measure is a rate, which uses women of reproductive age as the denominator. The primary objective of this study is to compare measures of association of contextual-level social factors and pregnancy-related mortality between live births and women of reproductive age as the denominator. A secondary objective is to estimate the associations of these contextual-level social factors with pregnancy-related mortality at a county level.

Methods: Data on pregnancy-related deaths was obtained from Maternal Mortality Review Committee's (MMRC's), with nine states contributing data. Live birth data from the National Center for Health Statistics (NCHS) birth data and women of reproductive age data from the American Community Survey (ACS) were measured at the county level, and stratified on year, race, and age. Family planning measures came from the Guttmacher institute, and race, poverty, and urban/rural measures came from the ACS. To model pregnancy-related deaths, random effects Poisson models were used with a random intercept fit for county. Rate ratios were calculated with 95% confidence intervals for each of the exposures and using each of the denominators, with additional models stratifying by race. To compare rate ratios across denominators, a ratio of ratios was used to assess the degree to which the denominator affected the exposure-outcome association.

Results: We assessed 322 pregnancy-related deaths from nine states in the US. In general, associations between county contextual exposures and pregnancy-related mortality in overall models using live births were similar to models using women of reproductive age. In stratified models, contraception need had a slightly stronger association in white women (RR=1.71, CI=0.79, 3.73), while percent rural had a slightly stronger association in black women (RR=1.76, CI=0.49, 6.41), although estimates were imprecise. For percent black, estimates stratified by race were below the null, suggesting a lower pregnancy-related mortality rate in counties with higher percent black population for both white and black women. Similar trends were seen in the stratified live birth models, except that higher percent black was associated with a higher rate ratio for black women (RR=1.96, CI=0.25, 15.44). Ratio of ratios comparing estimates showed that most estimates were slightly stronger for live births, except some estimates for percent black and percent rural. Finally, the black-white disparity was stronger using women of reproductive age as the denominator (RR=3.13, CI=2.34, 4.17 vs. RR=2.45, CI=1.84, 3.25).

Discussion: Using women of reproductive age as the denominator for pregnancy-related mortality instead of live births does not appear to alter observed associations with available measures of contraception need, although it does influence estimates for race and rurality. Future work should focus on untangling the interactions between race, rurality, unintended pregnancy, and pregnancy-related mortality.

Introduction:

In the United States, pregnancy-related mortality has increased in recent decades from 7.2 deaths per 100,000 live births in 1987 to 18.0 deaths per 100,000 live births in 2014.[10] In addition to having a trend counter to the decrease seen in most countries, there are stark racial disparities in maternal mortality in the United States. Non-Hispanic black women had a pregnancy-related mortality ratio 3.4 times higher than non-Hispanic white women between 2011-2013.[102]

Historically, maternal mortality has been measured in the United States using two primary systems. National Vital Statistics System (NVSS) uses death certificates, which indicate if a woman was pregnant or within 42 days of the end of the pregnancy at the time of her death, to define maternal deaths.[76] However, due to the limitations of death certificate and ICD-10 based classification of maternal deaths, a complementary national system called PMSS has been developed.[10] States identify possible pregnancy-associated deaths (with time period defined as while pregnant or within one year postpartum) through a ‘pregnancy checkbox’ on the death certificate, key words on the death certificate, or by linking death certificates to birth and fetal death certificates in the year prior to death. Medical epidemiologists at the CDC then review these deaths to determine which are causally linked to pregnancy (pregnancy-related) and assign a cause of death code. NCHS and PMSS provide crucial population-level data and trends over time but provide limited information on contributing factors and preventability of deaths.[11,14]

In contrast, state- and urban-based maternal mortality review committees (MMRC’s) have been proposed as one way to get more in-depth information on specific and actionable underlying causes and contributors to maternal deaths, as well as aggregating deaths for surveillance purposes.[11] While some MMRC’s are long-standing, there has been a recent effort to provide technical support and standardize the process through the Maternal Mortality Review Information Application (MMRIA) system.[14] MMRIA is a platform used by MMRC’s for entering, reviewing, and aggregating data used during the review process in a more comprehensive and standardized way.

When calculating pregnancy-related mortality ratios from these data sources, live births is typically used as the denominator. This means that the comparison group for maternal deaths are women who are pregnant and give birth to a live born infant; the implication, therefore, is that any exposure has a detrimental effect on maternal outcomes through the pregnancy, birthing, and post-partum processes. Any effects that lead to poor maternal outcomes due to the conditions under which a pregnancy was conceived cannot be evaluated, since the entire study population shares the characteristic of becoming pregnant. Additionally, the live birth denominator excludes a large number of early pregnancy miscarriages, terminations, and stillbirths. Using women of reproductive age as a denominator takes a wider view on maternal mortality as a women's health event, acknowledging that the adverse effects of contextual level determinants can occur through preconceptual health, the circumstances of the pregnancy, and the processes of pregnancy, birth, and post-partum. It allows effects on incidence of pregnancy to be captured. In a context of limited access to birth control and continuing violence against women, the risks posed from becoming pregnant are an important piece of the question of adverse maternal outcomes.[103,104]

Particularly when examining access to care, race, or other social factors, the influence on pregnancy incidence may be an important part of the pathway. Access to contraception and preconceptual care are thought to be associated with maternal mortality through direct effects of increasing pregnancies and indirect effects on maternal mortality once pregnant. Indirect effects imply that pregnancies that are unwanted or mistimed have higher adverse outcomes than wanted and properly timed pregnancies. Evidence has shown that shorter inter-pregnancy intervals are associated with the negative clinical outcomes of premature rupture of membranes and placenta previa, and it has been demonstrated that countries with higher access to contraception have the percentage of births with an age or parity risk factor drop from 75% to 35%.[38,105] Modeling estimates of the effect of contraception typically take these indirect effects into account by estimating change in MMR for unintended pregnancies, which may be higher than that for intended pregnancies due to differential risk profiles and abortion risks.[39] However, when estimating associations, the full effects of contraception access may not be captured by using a pregnancy-related mortality ratio conditional on being pregnant and having a live birth.

The primary objective of this study is to compare measures of association of contextual-level social factors and pregnancy-related mortality between live births and women of reproductive age as the denominator. A secondary objective is to estimate the associations of these contextual-level social factors (family planning, Title X clinics, poverty, racial composition, and rurality) with pregnancy-related mortality at a county level.

Methods:

Study Population and Data Sources

Data on pregnancy-related deaths was obtained from the MMRIA database, with nine states contributing data: Arizona (2016), Delaware (2009-2016), Georgia (2012-2013), Hawaii (2015), Illinois (2015), Mississippi (2016), North Carolina (2015), Ohio (2008-2016), and Utah (2015-2016). Any partially-completed years (that is, not all deaths in a given year had been reviewed) were excluded from analysis. This means that included years for a given state should include all pregnancy-related deaths that occurred in that year, and these deaths are each linked to county of residence and limited individual-level data on race and age. Since all pregnancy-related deaths should theoretically be known, counties with zero deaths are presumed to be true zeros and are included in the analysis.

Live birth data came from the National Center for Health Statistics (NCHS) birth data. Women of reproductive age data were obtained from the American Community Survey (ACS). These denominator data were measured at the county level, and stratified on year, race, and age to match the numerator data. The county-level exposures came from the Guttmacher institute for family planning measures and from the ACS for race, poverty, and urban/rural measures.

Data measures / Variables

The MMRIA system currently aims to capture all deaths in states using the system that are potentially pregnancy-associated. Pregnancy-associated deaths are defined as any death of a woman that occurs while pregnant or within a year after end of the pregnancy, regardless of location or duration of the pregnancy.[14] Among pregnancy-associated deaths, cases are divided into those determined to be related to pregnancy, meaning the pregnancy or its management contributed to the death; pregnancy associated but not related deaths, which are those that occur during the time period but are not due to the pregnancy; and pregnancy associated but unable to determine relatedness, where there is not enough information to determine if a causal link with pregnancy exists.[14] This study was limited to deaths determined by MMRC's to be pregnancy-related. Live births are defined as all births that result in a living child as recorded on a birth certificate. Women of reproductive age are women 15-44 years old.

Measures of family planning need came from Guttmacher Institute data, which is an institute committed to research on reproductive and sexual health. As part of that mission, they publish a periodic report on contraceptive need in the United States. This report uses data from the Census Bureau, American Community Survey, and National Survey of Family Growth to derive estimates of women in need of contraceptive services and supplies, and women in need of publicly funded contraceptive services and supplies, which are then modelled at a county level.[77] Women are defined as 'in need of contraceptive services and supplies' if they are sexually active, not known to be sterile, and are not pregnant or trying to get pregnant. Title X clinics are defined as sites that receive funding from the Title X federal funding program for family planning.[78] Percent poverty, percent non-Hispanic black, and percent rural were defined as the number people in each of these categories divided by the total population.

Individual level covariates for the pregnancy-related deaths and denominators were race and age. Race was defined as Non-Hispanic white, Non-Hispanic black, Hispanic, and other for the numerator. However, due to available information, for both denominators it was defined as Non-Hispanic white, black, Hispanic, and other. This could lead to some overlap of women in the black and Hispanic categories; for the included counties, however, this number was generally less than 1% of the overall population in that county.

Analysis

Descriptive statistics were calculated to examine the distribution of the outcome and exposures. To calculate tertiles for pregnancy-related mortality rates by county with small numbers of events, empirical Bayesian rate calculations were used to stabilize estimates. To model pregnancy-related deaths, Poisson, negative binomial, zero-inflated Poisson, and zero-inflated negative binomial distributions were considered. We ultimately chose to use a Poisson distribution to model all outcomes due to similarities in results between the different models. Random effects models were used to account for the nesting of women within counties, with a random intercept fit for county. Unadjusted and adjusted rate ratios were calculated with 95% confidence intervals for each of the exposures and using each of the denominators, with additional models stratifying by race. To compare rate ratios across denominators, a ratio of ratios was used to assess the degree to which the denominator affected the exposure-outcome association. SAS was used for all statistical calculations, except maps and empirical Bayesian estimations which were performed in Geoda.

Results:

In total, 322 pregnancy-related deaths were examined from nine states. The distribution of county pregnancy-related mortality rates using women of reproductive age (Figure 5-1) and live births (Figure 5-2) as the denominator were mapped with empirical Bayesian smoothing.

Figure 5-1. Pregnancy-related mortality rates, WRA denominator, smoothed empirical Bayesian methods

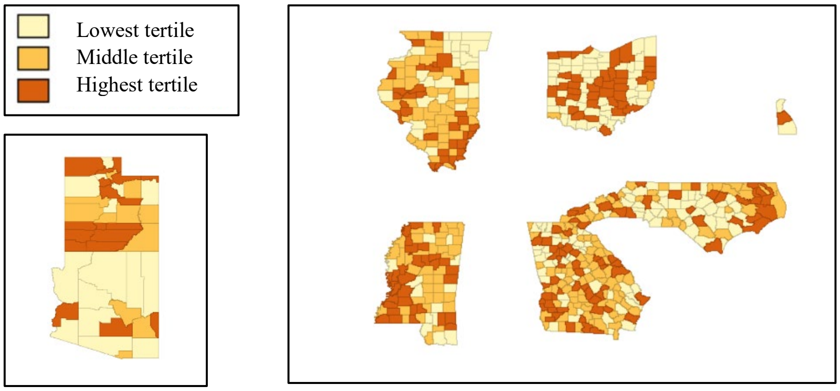


Figure 5-2. Pregnancy-related mortality rates, LB denominator, smoothed empirical Bayesian methods

Table 5-1 shows characteristics of the five exposure variables considered. The counties in this analysis had on average 17.5% living below the poverty line, 12.5% non-Hispanic black populations, 53.2% rural populations, 51.2% of women of reproductive age needed contraception, and 12.73 Title X clinics per 100,000 women of reproductive age.

Table 5-1. Characteristics of exposure variables

Variable	Mean (SD)	Range
Percent in need of contraception	0.512 (0.032)	0.455 – 0.631
Title X clinics per 100,000 population	12.73 (20.48)	0 – 181.8
Percent below national poverty line	0.175 (0.065)	0.045 – 0.487
Percent black	0.125 (0.166)	0 – 0.859

Percent urban	0.468 (0.272)	0 – 0.9995

Looking at the primary exposure of contraception need compared to other exposures, counties with the highest contraception need appear to have lower poverty, more non-Hispanic black residents, and be more urban compared to those with the lowest third of contraception need (Table 5-2). When comparing averages of the exposures by tertiles of pregnancy-related mortality, all exposures have a U-shaped relationship with the outcome, with counties with the middle third of maternal mortality having lower percent women in need of contraception, higher percent poverty, higher percent black, and higher percent rural (Table 5-3). However, on average, counties with the highest rates of pregnancy-related mortality still had higher levels of poverty, black residents, and rurality compared to those in the lowest third.

Table 5-2. Averages of exposures by level of contraception need

	Lowest third contraception need *mean (SD)*	**Middle third contraception need** *mean (SD)*	**Highest third contraception need** *mean (SD)*
% poverty	18.4 (6.4)	17.1 (7.1)	17.0 (5.9)
% black	10.6 (15.8)	12.1 (18.1)	15.1 (15.5)
% rural	69.9 (18.1)	58.4 (23.7)	29.7 (22.3)
# Title X per 100,000 WRA	16.2 (21.0)	14.9 (23.1)	7.6 (15.6)

Table 5-3. Averages of exposures by maternal mortality

	Lowest third maternal mortality *mean (SD)*	**Middle third maternal mortality** *mean (SD)*	**Highest third maternal mortality** *mean (SD)*
% contraception	51.3 (3.2)	50.0 (2.4)	51.7 (3.3)
% poverty	15.6 (5.7)	20.9 (7.1)	18.0 (6.3)
% black	7.6 (10.8)	22.0 (19.9)	13.4 (18.0)
% rural	46.1 (24.1)	68.7 (21.1)	53.5 (29.8)

# Title X per 100,000 WRA	8.0 (9.9)	19.4 (21.7)	14.8 (26.6)

The unadjusted rate ratio estimates from multilevel Poisson models comparing the highest versus lowest quartile of exposure are shown in Table 5-4. Most of the associations are close to null, although some estimates are imprecise. Percent below poverty line is the exception, with a rate ratio of approximately 1.5 for both live birth and women of reproductive age estimates.

Table 5-4. Unadjusted multilevel Poisson models, comparing highest vs. lowest quartile of exposure

	Rate ratio: Live birth denominator *RR (CI)*	**Rate ratio: Women of reproductive age denominator** *RR (CI)*
Percent of women in need of contraception	1.18 (0.74, 1.88)	1.08 (0.68, 1.73)
Number Title X clinics	1.06 (0.65, 1.72)	1.21 (0.75, 1.94)
Percent black	1.25 (0.82, 1.90)	1.14 (0.73, 1.79)
Percent below poverty line	1.51 (1.01, 2.26)	1.50 (0.99, 2.27)
Percent rural	1.18 (0.71, 1.96)	1.31 (0.78, 2.18)

Table 5-5 presents pregnancy-related mortality ratios using WRA as the denominator for highest versus lowest quartile of exposures, from a multilevel Poisson model adjusted for age and year at an individual level and other county-level exposures. Estimates are given for the total population, and then stratified by individual race into black and white women. Models were also considered that did not include percent in need of contraception since this measure may be highly correlated with other demographic variables. Adjusting for covariates brings all of the associations closer to the null in the total models. In the race-stratified models, some exposures show differences in magnitude of effect size by race. In particular, contraception need has a slightly stronger effect in white women (RR=1.7, CI=0.8, 3.7) and rurality has a slightly stronger effect in black women (RR=1.8, CI=0.5, 6.4), although estimates are imprecise. Interestingly, when stratifying by race, the direction of the effect of percent black changes, with counties with higher percentages of black women having lower maternal mortality rates for both white (RR=0.4, CI=0.2, 0.9) and black (RR=0.5, CI=0.1, 4.1) women. Additionally, the direction of association for number Title X clinics is different, with a higher number associated with higher mortality in black women but lower mortality in white women. However, in race-stratified models the estimates are very imprecise due to smaller numbers of events.

Table 5-5. Rate ratios comparing highest v lowest quartile of exposure (women of reproductive age)

	Total *RR (CI)*	**Total, no contraception** *RR (CI)*	**Black** *RR (CI)*	**Black, no contraception** *RR (CI)*	**White** *RR (CI)*	**White, no contraception** *RR (CI)*
Percent contraception[1]	1.28 (0.69, 2.38)		1.05 (0.31, 3.60)		1.71 (0.79, 3.73)	
Percent black[1]	1.08 (0.60, 1.97)	1.13 (0.65, 1.99)	0.52 (0.07, 4.06)	0.53 (0.07, 4.20)	0.42 (0.21, 0.88)	0.46 (0.23, 0.95)
Percent poverty[1]	1.35 (0.85, 2.14)	1.40 (0.89, 2.21)	1.15 (0.50, 2.63)	1.16 (0.51, 2.62)	1.31 (0.68, 2.56)	1.48 (0.77, 2.83)
Percent rural[1]	1.45 (0.73, 2.87)	1.23 (0.68, 2.21)	1.76 (0.49, 6.41)	1.71 (0.58, 5.00)	1.43 (0.60, 3.38)	1.04 (0.49, 2.21)
Title X clinics per WRA[2]	1.08 (0.65, 1.80)		1.28 (0.57, 2.86)		0.63 (0.28, 1.45)	

1. Adjusted for individual-level age and year of birth; county-level percent contraception, black, poverty, and rural
2. Adjusted for individual-level age and year of birth; county-level percent black, poverty, and rural

Table 5-6 shows the same information for rate ratios using live births as the denominator. In general, estimates of association between contextual exposures and pregnancy-related mortality in the total population model are slightly stronger when using live births, although again estimates are imprecise. Similar to results for women of reproductive age, estimates for white women are stronger than black women for percent contraception (RR=1.9 vs. RR=1.3) and stronger for black women for percent rural (RR=2.0 vs. RR=1.5). However, estimates for percent black are different compared to women of reproductive age. For total women and white women estimates are similar, but for black women the direction of the effect changes; living in an area with a higher percent black population is associated with a higher pregnancy-related mortality for black women, although the estimate is very imprecise (RR=2.0, CI=0.3, 15.7).

Table 5-6. Rate ratios comparing highest v lowest quartile of exposures (live births)

	Total *RR (CI)*	**Total, no contraception** *RR (CI)*	**Black** *RR (CI)*	**Black, no contraception** *RR (CI)*	**White** *RR (CI)*	**White, no contraception** *RR (CI)*
Percent contraception[1]	1.49 (0.80, 2.77)		1.34 (0.39, 4.62)		1.85 (0.86, 3.99)	
Percent black[1]	1.12 (0.67, 1.89)	1.17 (0.70, 1.96)	1.96 (0.25, 15.44)	1.99 (0.25, 15.66)	0.48 (0.24, 0.96)	0.53 (0.26, 1.05)
Percent poverty[1]	1.53 (0.97, 2.42)	1.57 (1.00, 2.46)	1.26 (0.55, 2.90)	1.27 (0.56, 2.89)	1.54 (0.80, 2.97)	1.70 (0.89, 3.23)
Percent rural[1]	1.48 (0.75, 2.92)	1.11 (0.62, 1.99)	1.96 (0.53, 7.29)	1.62 (0.54, 4.83)	1.51 (0.65, 3.51)	1.02 (0.49, 2.15)
Title X clinics per WRA[2]	0.95 (0.56, 1.61)		1.30 (0.58, 2.90)		0.61 (0.27, 1.40)	

1. Adjusted for individual-level age and year of birth; county-level percent contraception, black, poverty, and rural
2. Adjusted for individual-level age and year of birth; county-level percent black, poverty, and rural

To compare the associations between models using women of reproductive age as a denominator versus live births, a ratio of the rate ratios was calculated (Table 5-7). Almost all ratios are less than 1, indicating the association was slightly stronger for live birth estimates compared to women of reproductive age when rate ratios were both above the null. Two estimates were in opposite directions, so the estimate below the null was inverted so two estimates above the null are being compared. The only associations where women of reproductive age yielded larger effect sizes were for the effect of percent black among white women, and in estimates of percent rural when contraception was not adjusted for.

Table 5-7. Ratio of ratios, women of reproductive age vs. live births

	Total	**Total, no contraception**	**Black**	**Black, no contraception**	**White**	**White, no contraception**
Percent contraception	0.86		0.79		0.92	
Percent black	0.96	0.97	0.99[1]	0.95[1]	0.89[2]	0.88[2]
Percent poverty	0.88	0.89	0.91	0.91	0.85	0.87
Percent rural	0.98	1.11	0.90	1.06	0.95	1.01
Title X clinics per WRA	1.03[1]		0.99		1.03[2]	

1. One estimate was below the null, so that estimate inverted to be a harmful effect
2. Both estimates below the null, so ratio more than 1 indicates a stronger association for live births

Finally, to examine the impact of denominator on racial disparities observed, the effect of individual race was estimated between racial groups, controlling for other individual and county level covariates (Table 5-8). Using women of reproductive age as the denominator gave a higher estimate for the pregnancy-related mortality ratio for black vs. white women (RR=3.1 CI=2.3, 4.2 vs. RR=2.4 CI=1.8, 3.3). The estimate for Hispanic women vs. white women was also higher using WRA, while the estimates for other vs. white were similar.

Table 5-8. Black-white disparity, controlling for individual covariates and county level factors

	Live births *RR (CI)*	**Women of reproductive age** *RR (CI)*
Black v white	2.45 (1.84, 3.25)	3.13 (2.34, 4.17)
Hispanic v white	0.96 (0.60, 1.52)	1.28 (0.80, 2.04)

Other v white	0.81 (0.42, 1.54)	0.82 (0.43, 1.57)

Discussion

In summary, using women of reproductive age as the denominator in pregnancy-related mortality did not result in stronger associations with contraception need as hypothesized. However, it did change estimates for county-level percent black and percent rural, and it resulted in a larger magnitude estimate of black-white disparities for individual race.

These results could have occurred for several reasons. First, it could be that the association between percent of women in need of contraception and pregnancy-related mortality truly does not differ between these two denominators. This would mean that either contraception need is not associated with pregnancy-related mortality, or it is associated in the same way in live births as in the broader population of women of reproductive age. While the estimates were imprecise, there was some relationship between contraception and mortality, making the first possibility less likely as an explanation for the stronger effect using live births. That the association is the same may be more plausible if indirect effects of contraception on pregnancy-related mortality were stronger than the direct effects (that is, the strongest effects on maternal mortality come from more high-risk women being pregnant, which would increase the live birth ratio as well as the women of reproductive age ratio). Given evidence on the change in risk profile for areas with high versus low contraception, the indirect effects of contraception on pregnancy-related mortality likely are present; however, direct effects (simply increasing the number of women pregnant and thus at risk) should also exist, so the estimate for women of reproductive age should be equal to or greater than that for live births.[105]

Another possibility that could explain the lack of hypothesized difference is the measurement of contraception need used. The data from Guttmacher Institute is for women in need of contraception, regardless of whether this need is unmet. Therefore, the measure may not be a good proxy for women at risk of unintended pregnancy and thus at increased risk for pregnancy-related mortality. The lack of a good metric also could explain the null results for Title X clinics. While this is one approximation of access to care, it does not give much information on women served, amount of time open, or other important determinants of access. It could also be there is some confounding of the association between Title X clinics and pregnancy-related mortality by perceived contraception need. One study found that shorter distance to a family planning facility was not associated with unintended pregnancy and was associated with a higher teen pregnancy rate, which they concluded could be due to clinics being placed in high need areas.[42]

Finally, the variations in estimation of effects of race and rurality on pregnancy-related mortality may be important for understanding pathways by which these factors effect mortality. For race, part of the pathway is likely through unintended pregnancy; the percent of pregnancies that were unintended was 64% for non-Hispanic black women compared to 38% for non-Hispanic white women in the same year.[106] While differences in pregnancy intention by rurality are not as often reported, there have been some studies showing that there is a higher rate of unintended pregnancies and lower access to contraception in rural areas.[104,107] There could also be interesting interactions between rural and race effects; Platner et al found that black-white disparities in pregnancy-related mortality in rural areas were much lower than in urban areas in Georgia.[72] It also is significant to note that the racial disparity was more pronounced when using women of reproductive age as the denominator, even though the contextual effect of county-level race was not more pronounced. There is a need for more research on how rurality affects racial disparities, particularly given evidence of recent closures of rural hospitals or hospital obstetric units.[70,74]

Strengths and Limitations

This study used data from maternal mortality review committees, and thus was able to examine pregnancy-related deaths specifically and to link them to county-level exposures based on place of residence. Additionally, we were able to adjust for individual race and age since these variables were present in the MMRIA dataset. These deaths are from completed years of review, and thus should represent all pregnancy-related deaths from a given state in a given year.

While this study was able to utilize data from multiple states in the MMRIA system, the sample size was still relatively small which resulted in imprecise estimates, particularly when stratifying on race. Since only certain states contributed data, it was also difficult to determine any regional trends. When more data are available, future work could examine these trends by region, since race, rurality, and access to contraception may differ across the country.

Additional limitations with variables available included individual race classification and the limitations of available measures of access to contraception. While individual deaths were classified as non-Hispanic white, non-Hispanic black, Hispanic, and other, denominator data was classified slightly differently due to inability of ACS data to be stratified in this way. Women of reproductive age and live births were therefore classified as non-Hispanic white, black, Hispanic, and other. This means that some women who were black and Hispanic would be classified as black rather than Hispanic. However, we do not anticipate this would alter the denominators too much, as the overlap between these categories in the states analyzed was minimal. Finally, as previously discussed, the measures of access to contraception used in this study may not have been good measurements of the unmet family planning need we were trying to capture. This limits conclusions that can be drawn about the effect of access to contraception and pregnancy-related mortality.

Conclusion

In conclusion, using women of reproductive age as the denominator for pregnancy-related mortality instead of live births does not appear to alter observed associations with available measures of contraception need, although it does influence estimates for measures of race and rurality. Future work should focus on untangling the interactions between race, rurality, unintended pregnancy, and pregnancy-related mortality.

CHAPTER 6: DISCUSSION

Summary of findings

In this dissertation, we examined women's access to healthcare and maternal and child mortality using data from two novel surveillance sources. In general, we found that a social autopsy tool to collect information on women's access to care for neonatal deaths had high acceptability in Sierra Leone. Next, using data from that social autopsy tool, we found that delays in women's access to prenatal and obstetric care, particularly delays after arriving at the health facility, were associated with neonatal mortality. Finally, in the United States, we found a weak association between contraception need and pregnancy-related mortality irrespective of whether the denominator was live births or women of reproductive age.

In Chapter 3, we explored the acceptability and validity of a social autopsy questionnaire to collect information on women's access to prenatal and obstetric care following a neonatal death in Sierra Leone. We found that in this context, this questionnaire on socioeconomic status, household factors, and access to healthcare was generally accepted since it was linked to improving children's health. Participants reported that in general community members would be willing to answer questions about these topics if the interviewer built a good rapport with them. However, participants discussed stigma in the community against taking a child to a traditional healer or not taking them to a health facility could lead to response bias in the social autopsy. A pilot validation study conducted to assess questions on access to care compared to a qualitative interview found that for many participants the structured questionnaire adequately captured information on access to care; however, in some cases, participants underreported barriers on the structured questionnaire compared to the open-ended interview.

In Chapter 4, at the same site in Sierra Leone, we conducted a case-control social autopsy study of 53 neonatal deaths and 140 control neonates. Of neonatal cases, 26.4% of the mothers experienced at least one delay during pregnancy or labor and delivery, with the most common being a delay in receiving care once at the facility (18.9%). In contrast, 18.6% of mothers of neonatal controls experienced some barrier, and the most common was a delay in deciding to seek care (15.0%). When adjusted for confounders, experiencing any barrier was associated with a 1.68 increased odds of death (CI=0.77, 3.67), and specifically a delay in receiving care once at the facility was strongly associated with death (OR=19.15, CI=3.90, 94.19).

Stratifying on early vs. late neonate, effects were stronger in late neonates; for example, the effect of each increasing barrier was a 2.14 increased odds of death (CI=1.05, 4.35) vs. 1.38 in the non-stratified model. We also stratified on self-reported medical complications (yes vs. no) and found that there were large differences for any barrier, each additional barrier, and type 1 delays; these exposures were associated with a decreased odds of death in those who reported medical complications, while they were associated with increased odds of death in those who had not experienced medical complications. All stratified estimates were relatively imprecise due to the small sample size in each category; however, of note, type 3 delays remained significantly associated with death in all subgroups except early neonates.

To assess the effect of case selection and exposure misreporting, we performed sensitivity analyses. For all selection probabilities considered, the bias adjusted odds ratio was further from the null than the unadjusted estimate, suggesting the true association may be stronger than what we observed. The misclassification bias analysis shows that sensitivity for exposure classification among controls would have to be approximately 0.6 to bring the association of barrier score and mortality to null, assuming that controls are more likely to misremember delays encountered. This suggests that while exposure misclassification may have affected the results, misclassification would have to be substantial to bring the results to a null association.

Finally, in Chapter 5, we assessed 322 pregnancy-related deaths and county-level measures of access to contraception, race, poverty, and rurality from nine states in the US. We used multilevel Poisson models adjusted for individual and county level covariates and examined modelling results using women of reproductive age and live births as the denominator for pregnancy-related mortality rates. We did not find evidence that rate ratios were stronger for a measure of contraception need using women of reproductive age as the denominator as originally hypothesized.

For women of reproductive age, estimates were slightly above null for all exposures, although none were significantly different than null. Stratifying by black and white women, we found that contraception need had a stronger association in white women (RR=1.71, CI=0.79, 3.73), while percent rural had a stronger association in black women (RR=1.76, CI=0.49, 6.41). For percent black, estimates among white women and among black women were both below the null, suggesting a lower pregnancy-related mortality rate in counties with higher percent black population. In general, associations in total models using live births were stronger, although also imprecise. Similar trends were seen in the stratified models as women of reproductive age stratified models, with the exception of percent black. Using live births as the denominator, higher percent black was still associated with lower mortality for white women, but it was associated with a higher rate ratio for black women (RR=1.96, CI=0.25, 15.44).

Ratio of ratios were calculated to compare estimates between women of reproductive age and live birth models, and showed that most estimates were slightly stronger for live births, with the exception of some estimates for percent black, and estimates for percent rural when contraception was not included in the model. Finally, racial disparities in pregnancy-related mortality were examined using each denominator. The black-white disparity was stronger using women of reproductive age as the denominator (RR=3.13, CI=2.34, 4.17 vs. RR=2.45, CI=1.84, 3.25).

Implications and future directions

Collectively, these results demonstrate the importance of women’s access to care and maternal and child mortality, and they demonstrate process and benefits of further enhancing maternal and child mortality surveillance systems. These results tie into current efforts to increase measures of social determinants, broadly, into mortality surveillance through tools such as social autopsy and measures of health equity in MMRIA. Krieger and colleagues have argued that a lack of data on socioeconomic status in the United States is a reflection of structural inequities and has precluded accountability for disparities that exist.[108] In the framework of Krieger's ecosocial theory, this limits accountability at a policy or societal level for the forces that drive the distribution in maternal and child outcomes along social lines.

There are several future directions this line of research and surveillance efforts could take. Broadly, measurement of access to care could be linked to causes of death to give insight into mechanisms by which social forces are influencing mortality. This would connect to Krieger's idea in ecosocial theory of pathways to embodiment, or ways by which our context becomes part of our physical health. Given the depth of biological and clinical data present in CHAMPS and MMRIA, there is opportunity for rich analysis of pathways between access to care factors examined in this dissertation and clinical presentations or causes of death. Particularly as the number of cases in each data set grows, and thus the power to analyze by subgroups of cause of death, interesting questions can be examined.

For Chapter 3, additional work should focus on standardizing a social autopsy tool. While the World Health Organization has a standardized Verbal Autopsy, they have not endorsed a complementary social autopsy tool. The growing number of studies employing a social autopsy in recent years demonstrates the desire to collect this data, but with disparate tools in use it is difficult to compare across studies. The acceptability results from Chapter 3 combined with experiences implementing the social autopsy questionnaire from Chapter 4 suggest that it is feasible to implement a social autopsy tool in routine mortality surveillance. With increasing studies using this tool and the feasibility of using it in surveillance, an effort should be made to revise and standardize a form to be used across mortality surveillance systems.

As part of this revision process, a thorough validation study of the healthcare seeking and barriers questions should be conducted. As we identified in our data from Chapter 3, response bias for sensitive questions is a concern. In results from Chapter 4 we adjusted for the possible bias of underreporting of barriers by control participants and estimated the sensitivity would have to be 0.6 for the estimated effects to become null. However, if there is also potential for cases to overreport healthcare seeking behaviors or barriers to care, the direction and magnitude of the bias becomes more difficult to estimate. A validation and thorough consideration of the phrasing and ordering of questions on the social autopsy tool is thus necessary, including guidelines on adaptation for different cultural contexts.

The results from Chapter 4 warrant further examination due to the strong association of Type 3 barriers and weak or inverse associations of Type 1 and 2 barriers with neonatal mortality. A more thorough examination of the deaths reporting Type 3 delays could give insight into how this delay is occurring and influencing survival or death of neonates in this setting. An investigation at the facility level could further highlight areas for improvement. Particularly as an actionable outcome, beyond future research, the strong influence of delays at the facility on neonatal death should prompt an increased focus on staffing, stocking of medicine, and wait times at facilities.

Finally, the results from Chapter 5 leave many questions for future consideration. The association between family planning need and pregnancy-related mortality was not stronger when using women of reproductive age as a denominator as we hypothesized. However, the measure used for women in need of contraception was problematic, since it is not a measure of unmet need but rather the number of women who need contraception regardless of whether they have access. This study could be repeated with a better measure of family planning need that is unmet to better approximate women at risk of unintended pregnancies. It also highlights the need for better data available at a county level on unmet family planning need. Another direction future research could take would be to focus on the differences in results between denominators for contextual effects of racial composition and rurality. A more thorough analysis of the relationship between race, rurality, and pregnancy-related mortality could explain these results, as well as elucidate to what extent they depend on unintended pregnancy as a pathway. Particularly given the distribution of race and rurality in the states examined, an analysis by region may uncover associations obscured by combining all nine states together. Additionally, as more states and more years become available and the total number of events increases, estimates will become more precise and may clarify relationships that differ between region.

Strengths and limitations

Strengths of this dissertation include the investigation of measurements of access to care in two novel enhanced surveillance systems. Situating this research in the context of CHAMPS and MMRC's allowed us to leverage features of each system such as case ascertainment and ability to collect or link to measures of access to care. The exploration of acceptability and validity in Chapter 3 drew on the strengths of experienced interviewers in the community and perspectives from community members who varied in age, gender, and position in the community. The social autopsy case-control study in Chapter 4 was a systematic evaluation of differences in care-seeking during pregnancy and labor and delivery for neonatal deaths and neonatal controls. The analysis of MMRIA data in Chapter 5 linked pregnancy-related deaths to county-level exposure data and was able to adjust for or stratify on individual age and race. Additionally, since these deaths are from completed years of review, they should represent all pregnancy-related deaths from a given state in a given year.

There are several limitations of the research in this dissertation. In Chapter 3, one major limitation is that interviews were conducted with community members who had not yet participated in a social autopsy questionnaire. Due to ethical concerns about burden on grieving parents, interviews were not conducted after a social autopsy questionnaire had been administered, which could have given additional insight into experiences of the interview and evolving views of acceptability in the community. We were also not able to fully explore concerns about validity of questions on access to care that came out of the qualitative acceptability interviews, and conclusions from a small validity sub-study were limited.

In Chapter 4, one limitation was imprecise estimates due to a relatively small sample size, particularly when stratifying on neonatal age and medical complications. Selection cases primarily from facility births and misclassification of exposure primarily by controls were potential sources of bias. A bias analysis showed that differential selection of cases from facilities should bias the results towards the null, so the true association would be stronger than the observed association. However, misclassification of the exposure could have biased the observed estimate away from the null. The true extent of bias due to misclassification was difficult to determine due to uncertain parameters for sensitivities and specificities for the questions. Finally, there could be residual confounding by medical complications, since this was self-reported by women and also does not capture any information about severity of complications. Women who have symptoms during pregnancy or labor and delivery may be more likely to seek care, and also more likely to have a neonatal death occur. If barriers are a ubiquitous problem when seeking care, increased care seeking could lead to more reported barriers; thus, it would be the initial reason for care-seeking rather than the barriers that would be contributing to the death.

In Chapter 5, one main limitation with the planned analysis was the data available on contraception need and access to family planning care. The variable from Guttmacher Institute is for women in need of contraception, regardless of whether this need is unmet. Therefore, the measure may not be a good proxy for women at risk of unintended pregnancy and thus at increased risk for pregnancy-related mortality. The lack of a good metric also could explain the null results for Title X clinics. While this is one approximation of access to care, it does not give much information on women served, amount of time open, etc, which are all also important determinants of access. Additionally, while this study was able to utilize data from multiple states in the MMRIA system, the sample size was still relatively small which resulted in imprecise estimates, particularly when stratifying on race. Since only certain states contributed data, it was also difficult to determine any regional trends. When more data is available, future work could examine these trends by region, since race, rurality, and access to contraception may differ across the country.

Conclusion

In conclusion, measures of women's access to reproductive and obstetric care are important to include in maternal and child mortality surveillance systems. We found evidence that inclusion of a survey to measure these questions was acceptable in Sierra Leone. Using that survey, we found that delays in accessing prenatal and obstetric care, particularly delays once at the health facility, were associated with neonatal deaths. When examining if population at risk affected the association between a measure of contraception need and pregnancy-related mortality in the United States, we did not find differences between live births and women of reproductive age. However, differences in association for race and rurality suggest access to family planning and unintended pregnancy may be an important contributor to observed disparities in pregnancy-related mortality. Future work should focus on refining and optimizing measures of social determinants and access to care specifically; testing pathways by linking social factors to specific clinical features and causes of death; and examining different groups of women or children when large enough numbers exist in CHAMPS and MMRIA to perform subgroup analyses.

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