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Identifying behavioral, demographic, and clinical risk factors for delayed access to emergency obstetrical care in preeclamptic women in Port au Prince, Haiti

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Dissertation

IDENTIFYING BEHAVIORAL, DEMOGRAPHIC AND CLINICAL RISK FACTORS FOR DELAYED ACCESS TO EMERGENCY OBSTETRICAL CARE IN PREECLAMPTIC WOMEN IN PORT AU PRINCE, HAITI

by

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ABSTRACT

Objectives:

We conducted a mixed methods study of delayed access to emergency obstetrical care among preeclamptic and non-preeclamptic women in Port au Prince, Haiti, grounded in the Three Delays model of Thaddeus and Maine. The primary objectives were to identify factors affecting delays in accessing care and clinical consequences of delays.

Methods:

524 surveys were administered to women admitted to the Médecins Sans Frontières (MSF) obstetric emergency hospital. Survey questions addressed demographic, clinical, and behavioral risk factors; first (at home), second (transport) and third (health facility) delays; and clinical outcomes for women and infants. Bivariate statistics were used to assess relationships between preeclampsia status and delay, and between risk factors and delay. Twenty-six survey participants with lengthy delays (> 6 hours) were chosen for interviews, which elicited details about delays women experienced. Data were analyzed using a grounded theory approach.

Results:

We found long delays to accessing care for preeclamptic women (median 5.0 hours, IQR 10.5, vs. 4.0 hours, IQR 5.0, for non-preeclamptic women, $p<0.01$), primarily due to delays at home before leaving for the hospital (median 2.6 hours, IQR 10.6). No demographic, clinical, or behavioral factors were related to access to care. Women's health prior to pregnancy was not associated with delays, with the exception of preeclamptic women who had previously seen a doctor, who had significantly longer delays than women who had not previously seen a doctor (22.8 hours versus 11.2 hours, p=0.02). Long delays for both preeclamptic and non-preeclamptic women were not associated with poorer clinical outcomes. Although the MSF hospital is free of charge, financial barriers at other hospitals limited access to emergency obstetric care for many women, who commonly experienced non-evidence-based care, including inappropriate education from antenatal care providers when diagnosed with hypertension or preeclampsia.

Conclusions:

Pregnant women with preeclampsia in Port au Prince reported significant delays in accessing emergency obstetric care. Many delays stemmed from poor quality antenatal care services, which fail to screen, treat, or educate women appropriately. Improvements should be made in education and supervision for antenatal care providers, and in accessibility of emergency services at public hospitals in Port au Prince.

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List of Abbreviations

BEmONC	Basic Emergency Obstetric and Neonatal Care
CEmONC	Comprehensive Emergency Obstetric and Neonatal Care
CRUO	Centre de Référence des Urgences Obstétricale (Emergency Obstetrical Center- MSF Hospital in Port au Prince)
DHS	Demographic and Health Survey
EmONC	Emergency Obstetric and Neonatal Care
GHESKIO	Groupe Haïtien d'Étude du Sarcome de Kaposi et des Infections Opportunistes (Haitian Group for the Study of Kaposi's Sarcoma and Opportunist Infections)
IUGR	Intrauterine Growth Restriction
LAC	Latin America and Caribbean Region
MDG	Millennium Development Goal
MSF	Médecins Sans Frontières (Doctors Without Borders)
MSPP	Ministry of Public Health and Population
PEPFAR	President's Emergency Plan For AIDS Relief
PMTCT	Prevention of Maternal to Child Transmission (of HIV)
SONUB	Soins Obstetrique et Neonatale d'Urgence - de Base (Basic Emergency Obstetric and Newborn Care)
SONUC	Soins Obstetrique et Neonatale d'Urgence- Complet (Comprehensive Emergency Obstetric and Newborn Care)
SDG	Sustainable Development Goals
STI	Sexually Transmitted Infection
UNDP	United Nations Development Program
UNFPA	United Nations Population Fund
WHO	World Health Organization

Chapter 1: Significance and Study Aims

Case Presentation:

On October 1, 2014, Marie (not her real name) arrived at the Médecins Sans Frontières hospital in Port au Prince, Haiti. Marie, 16 years old and pregnant with her first child, had suffered an eclamptic seizure. She and her baby died within minutes of arriving at the hospital, despite the best efforts of the staff. Marie's death, and that of her baby, most likely could have been prevented with earlier medical care. However, Marie did not arrive at the hospital in time.

Introduction

Women and babies die at higher rates in Haiti than anywhere else in the Western Hemisphere. Though just an hour plane trip away, Haitian women have a one in eighty lifetime risk of dying of pregnancy complications, as compared to one in 1,800 in the United States.[1] The availability and use of emergency obstetrical care in the context of maternal health problems such as preeclampsia are essential to prevent both maternal and neonatal mortality. The lack of this appropriate emergency obstetrical care in Haiti leads to preventable deaths. Though some progress has been made, much is still unknown about why some women and infants do not receive appropriate care to prevent death.

Delays to access emergency obstetric care often mean the difference between life and death when a pregnancy complication occurs. The majority of Haitian women deliver their infants at home, either due to preference or lack of other options. When complications occur, women need access to emergency care. Delays to leaving home, or delays to reaching the hospital are related to individual, family, cultural, and contextual factors. Women in urban Haiti may face many delays to receive appropriate emergency obstetric care, but there is no research examining these risks. Research in rural Haiti has

found a wide range of obstacles that women need to overcome, but corresponding research in urban Haiti is lacking.

Access to emergency obstetric care is especially important in Haiti, where complications of pregnancy such as preeclampsia are very prevalent. Preeclampsia, when not treated correctly and swiftly, can lead to both perinatal and maternal morbidity and mortality. However, little research exists that describes the particular risks for women with complications of pregnancy like preeclampsia.

Medécins Sans Frontières (MSF) has been providing health care in Haiti since 1991. An international medical humanitarian organization, MSF's presence in Haiti assures adequate emergency obstetric care for the large population of women living in urban Port au Prince. Despite the presence of several large state-run university hospitals, the availability of emergency obstetric care in Port au Prince is limited due to human resource constraints and budget shortfalls within the Haitian Ministry of Public Health and Population (MSPP).

MSF offers free care to any pregnant woman meeting admission criteria for obstetric emergencies, including preeclampsia and eclampsia. In 2014 MSF delivered, on average, more than four hundred women per month, more than twenty-five percent of whom had preeclampsia or eclampsia. Despite the best efforts of MSF staff, some of these patients experience poor maternal or neonatal outcomes. However, the current program is not organized in a way to identify those women or neonates most at risk for poor outcomes. The program only cares for women and infants at the moment of labor and birth; as such, limited data is available regarding antepartum risk factors.

This dissertation will examine the research surrounding maternal and perinatal mortality in Haiti, and the effects of delayed access to care during obstetrical emergencies. While researchers have examined some of the risks for delayed access to obstetric care in rural Haiti, no corresponding research exists for urban Haiti. This study will examine behavioral, clinical and demographic risk factors for delayed access to emergency obstetrical care. Preeclampsia and eclampsia, hypertensive disorders of pregnancy, are especially prevalent in Haiti. A detailed examination of the risks of preeclampsia and eclampsia, and the risks of delayed access to care among this population will be outlined.

Chapter two will examine the Haitian context, public health system and problems, focusing on maternal and perinatal mortality. Chapter three will discuss the research regarding maternal and perinatal mortality in Haiti, the programs that have attempted to address the problem, and the specific risks for women with preeclampsia or eclampsia. The Three Delays model, which describes delays to accessing emergency obstetric care in low-income settings, will be discussed in relation to the Haitian context. Chapter four will present the research methodology by which we examined the risks for delayed access to emergency obstetrical care among urban Haitian women. Chapter five presents the results of the quantitative survey of women who were admitted to the MSF CRUO hospital, and Chapter six provides the findings from the qualitative interviews with a subset of those women who experienced long delays. A discussion of the study's findings, and its limitations, follows in Chapter seven. Finally, Chapter eight reviews the study's conclusions, and offers recommendations based on the study findings.

Study Aims

This dissertation aimed to identify and analyze predictors of delayed access to emergency obstetrical care in women and neonates admitted to an obstetric referral hospital in Port au Prince, Haiti. Specifically, clinical, demographic and behavioral risk factors were identified that led to delays in deciding to seek care or to reach the hospital. Poor maternal and perinatal clinical outcomes were measured, and their associations with the risk factors and with delayed access to care were assessed. Women with preeclampsia, and women with normal pregnancies who were admitted to an MSF obstetric hospital were questioned about their demographic, clinical and behavioral risk factors. A subset of preeclamptic women participated in in-depth interviews to add nuance and depth to the understanding of delayed access to care. The results of the study will be used to inform MSF surveillance activities, to target women most at risk for delayed access.

Chapter 2: Background

Haitian Context and History

Maternal and perinatal mortality are intimately linked with the context in which they occur. The deaths of pregnant women and babies in Haiti stem most proximately from poor access to emergency obstetric care. However, more distally, the context and history of Haiti are as much at play.

The history of the small island nation of Haiti is closely linked with the themes of slavery, colonialism and racism that have affected many other countries around the world. First "discovered" by Christopher Columbus in 1492, the island of Hispaniola, which includes the current nation of Haiti, quickly became a profitable source of many products for its colonizers. Brutal repression of the transplanted African slaves by their colonial masters led the way for the world's first free black nation, after the slaves defeated their captors in 1804. However, interference by world powers, along with ongoing political upheaval continued throughout the next 200 years. Haiti was led by a succession of short-lived dictators, and power was transferred by force.

Modern Haiti (Figure 1) has been shaped by the long rule of two dictators, the father-son Duvaliers. Francois Duvalier, or “Papa Doc” led Haiti from 1957 to 1971. He is known today for his brutally repressive regime. His son Jean-Claude Duvalier, or “Baby Doc”, continued those practices after taking over control of the “presidency for life” from his father, from 1971 to 1986.[2] After a long period of stable but autocratic rule, Haiti entered another period of turmoil after the end of the Duvalier era. Jean-Bertrand Aristide came to power twice, and was exiled twice. Military rule, United

States military interventions, and widespread brutalization of the population led to migrations of Haitians to neighboring countries. After the 2004 *coup d'état* overthrowing Aristide, the Haitian army was disbanded, and the United Nations peacekeeping force installed. In 2015, another period of instability began in Haiti, as contested elections left the country without an elected president.

Figure 1. Map of Haiti

Political turmoil was augmented by natural disaster following the massive earthquake of January 12, 2010. The 7.3 magnitude quake struck just off the coast of the capital city Port au Prince, and killed hundreds of thousands of people instantly.[3] Millions of people were left homeless after large sections of the urban area were flattened. As of 2014 more than 100,000 people remained in internally displaced person camps, more than four years after the earthquake.[4] The massive humanitarian influx that followed the earthquake has been well documented, and continued for years after the event, although

with reduced intensity.

Even before the earthquake struck, urbanization trends in Haiti had increased the numbers of Haitians living in Port au Prince. Migrations to the city continued even after the earthquake; people were perhaps encouraged to come by the provision of humanitarian aid that was delivered. At the end of 2014, almost 200 camps remained.[4] However, the distinction between the camps and the urban slums also found in Port au Prince is now academic. Many people in Port au Prince, whether in slums or camps, live in extremely vulnerable conditions, without access to safe water, adequate sanitation, or hygiene measures.

Haiti also suffers from extreme income inequality, which is nowhere more evident than in the capital city. Residents living in flooded, sewage-filled slums are pressed up against the luxury hotels and mansions of affluent Haitians, as well as the houses and offices of the many international aid agencies. The United Nations Human Development Index ranks Haiti 168 of 187 countries.[5] This multidimensional score includes such metrics as average years of schooling, life expectancy, and measures of inequality. Haiti's low ranking on the Human Development Index reflects the many challenges facing this country, including in public health.

In addition to low measures on health and education, Haitian society has also been described as oppressive to women. Davis and Bookey write that "[g]ender discrimination in Haitian society systematically obstructs women from preventing or addressing injustice against them, and strengthens other forms of structural oppression such as economic and political discrimination."[6] This discrimination can lead to increased

vulnerabilities of women and girls, including limiting their access to healthcare, and how healthcare services are made available to them.

Haitian Public Health System

Income and gender inequality are two of many risks facing the Haitian people. Haiti's population suffers from some of the highest rates of disease and has the lowest life expectancy outside of Sub-Saharan Africa. Public health care systems throughout Latin America, and specifically in Haiti, have not succeeded in easing the suffering of the poorest, who are most at risk for disease.[7] Lack of access to health care is also identified by Haitians themselves as a major concern.[8]

Haiti's public health system has been characterized as one of the weakest in the Western Hemisphere.[9] Chronic underfunding and understaffing have led to Haiti's wide range of poor health indicators.[9] Maternal and child health indicators are particularly worrisome. Haiti's maternal mortality ratio and its infant mortality rate are the worst in the Western Hemisphere.[10] There are less than 500 obstetricians or midwives in the entire country, far below the World Health Organization recommendation.[11]

The MSPP has ten health branches, one for each of the country's ten departments, equivalent to a state or province. Each of these ten MSPP branches is responsible for independently managing the health staff and structures in their department, with funding from the MSPP. The West department, which includes the capital city Port au Prince, has the majority of hospitals in the country, as well as the highest concentration of doctors and nurses.[12] About 45% of the Haitian population lives in Port au Prince. The rate of urban population growth is almost 4% per year, as compared to an overall Haitian growth

rate of 1.3%.[13]

However, as in many poor countries, the presence of public hospitals does not necessarily translate into access to quality health care for poor people. Haiti's public hospitals are crowded and poorly managed, suffer from staff shortages and strikes, lack appropriate supplies and medications, and are poorly funded.[14] Haiti's affluent population typically seeks care in private hospitals, or travels abroad for care. Obstetric and neonatal care is typical of many public health services in Haiti—insufficient and of poor quality.[12] While almost all Haitian women receive antenatal care, almost two thirds of women (67%) deliver at home. Even in Port au Prince, where access to care is nominally better, thirty-eight percent of women continue to deliver at home.[3]

Health Issues in Urban Haiti

Access to obstetrical care is one of many health issues affecting Haitian people. Urbanization in Haiti has led to greater and greater proportions of the country's population living in Port au Prince. There are specific health consequences of this urbanization trend, which may also affect pregnant women. Port au Prince is a sprawling city of approximately two and a half million people. As in many low-income countries, many urban residents live in slums characterized by shoddy housing, limited sanitary facilities, poor drinking water availability, and violence.

Urban areas are increasingly the focus of public health interventions, as the risks of urbanization are further described.[15] The majority of the world's population now lives in urban zones, as will soon be true in Haiti.[16] The World Health Organization has recognized the specific health issues facing urban residents, like those in Port au Prince,

in creating their Healthy Cities initiative.[17] Increased health risks of urban areas can include greater exposure to both indoor and outdoor air pollutants, obesity, natural disasters, poor sanitation and workplace dangers.[18] On a structural level, themes of violence and marginalization create inequalities in cities.[19] These inequalities, in turn, worsen other health risks.

Health risks of urban living include risks of natural disasters having more concentrated impact, like the earthquake that struck Haiti in 2010. The damage to Haiti's public health system—both in terms of physical buildings as well as loss of life——was significant. Although Haiti became the recipient of billions of dollars of foreign aid, scars of the earthquake still remain. For example, five years after the earthquake, the University General Hospital in Port au Prince remained under construction.

A number of research studies have examined the specific health issues faced by residents of Port au Prince. Specific research articles have noted increased risks of violence[20], cholera[21], HIV risk, STI risk[22], vector borne disease[22], disaster risk[23], sexual violence[24], anemia[25], environmental risk, and lower rates of health care access due specifically to violence[20], and lower coverage of mass-drug administration for filariasis[26]. No comparable research has addressed the specific risks of urban living for pregnant women living in Port au Prince.

The experience of pregnancy for a woman living in Port au Prince is likely quite different than that of a Haitian woman living in a rural area. Urban pregnant women must understand and negotiate a range of context-specific barriers, including transportation, gang violence, corruption among health staff, and overcrowding of public

hospitals. High levels of inequality, as are found in Port au Prince, are also known to worsen health. While the number of obstetric hospitals suggest that urban Haitian women have better access to emergency obstetric care[27], myriad factors may inhibit access. Many wealthy, urban Haitian women choose to leave the country to deliver, speaking to the difficulty of receiving quality health care in Haiti, even for those with means.

Global Efforts to Improve Maternal and Child Health

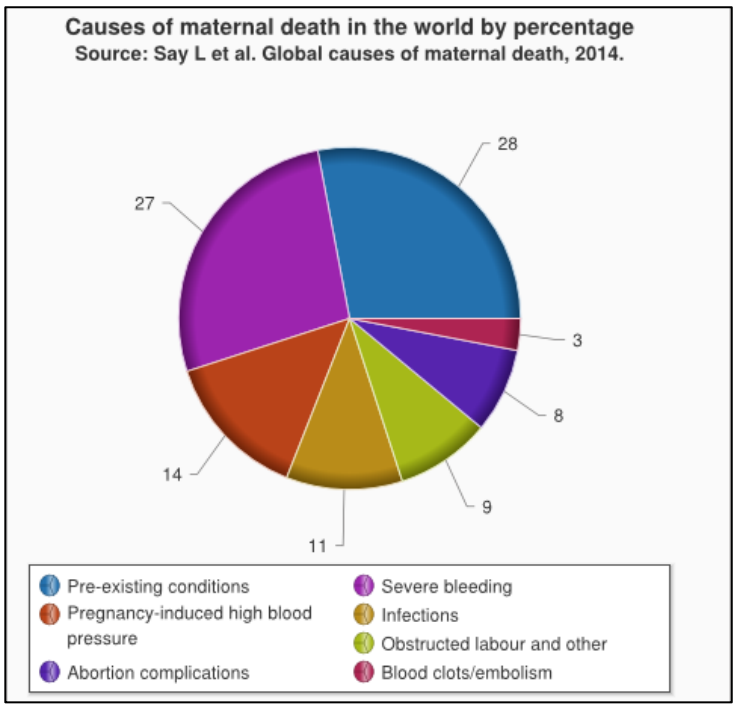
Understanding the causes of maternal and infant mortality, and addressing them, has been a major focus of public health efforts around the globe, including in Haiti. The Millennium Development Goals (MDGs), adopted by world leaders in 2000, targeted reductions in both maternal and infant mortality.[28] Haiti is one of many low-income countries that attempted to achieve these goals by 2015.

Starting with the Safe Motherhood Initiative in 1987, several worldwide initiatives have focused attention, funding and resources on lowering both maternal and neonatal mortality. Most programs operating at the time of the study to address these problems used the MDG framework, which helped countries plan approaches to meeting their targets.[29] The MDGs number 4 and 5 set goals for reductions in both child and maternal mortality.[28] Worldwide targets were not met by the 2015 deadline, though many countries, like Haiti, made some progress towards many of the objectives. The Sustainable Development Goals, developed by the United Nations in 2014, set new global targets, and also include a continued effort to achieve reductions in maternal and child mortality.[30]

Maternal Mortality

Maternal mortality is defined as the death during pregnancy or within forty-two days of the end of a pregnancy due to any cause related to the pregnancy or its management.[31] Accidental deaths, for instance due to a road traffic accident, would not be considered related to pregnancy. The worldwide burden of maternal mortality has decreased by about half since 1990.[32] Ninety-nine percent of the almost 300,000 deaths yearly occur in low-income countries such as Haiti, where poor public health infrastructure, among other problems, prevents timely and effective treatment of obstetric complications. Leading causes of maternal death include postpartum hemorrhage, hypertensive disorders of pregnancy, infections and obstructed labor (Figure 2).

Figure 2. Causes of worldwide maternal deaths



Source: Say, L. *et al*. Global causes of maternal death: a WHO systematic analysis. *Lancet Glob. Heal*. **2,** e323–e333 (2014).

Millennium Development Goal 5a aimed to reduce by three quarters the maternal mortality ratio. Worldwide maternal deaths dropped by 47% from 1990 to 2010, with greater gains made in Asia.[32] Some regions, notably Africa, have had much smaller reductions in maternal deaths. Haiti made progress in lowering the maternal mortality ratio, though the reported maternal mortality ratio figures are very unreliable. The MSPP reported maternal mortality figures that were more than 50% lower than United Nations interagency estimates.[12] Interagency estimates of maternal mortality in Haiti show a 43% reduction in maternal mortality between 1990 and 2013.[12]

Perinatal mortality: Early neonatal death

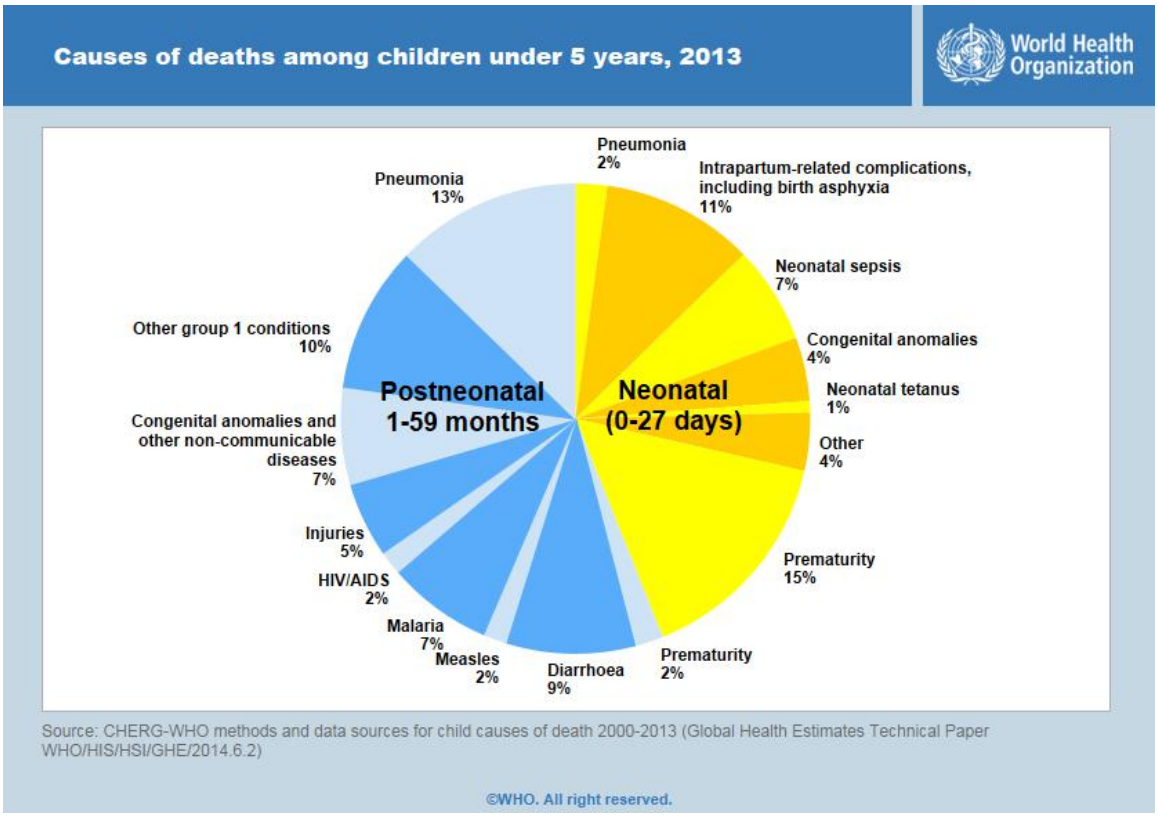
The World Health Organization defines the perinatal period as twenty-eight completed weeks of gestation to one week post-delivery—encompassing both the fetal and early neonatal period.[33] Emergency obstetric care is designed to prevent perinatal mortality. Deaths during the perinatal period are closely linked to maternal health and interventions, including timely treatment of obstetric complications. Perinatal deaths after twenty-eight weeks gestation and prior to delivery are defined as stillbirths, while deaths after delivery up to seven days of life are considered early neonatal deaths.[34] Every year, about three million babies die in the first month of life, and another three million are stillborn. As with maternal mortality, ninety-nine percent of those deaths occur in low income countries.[34] Programs to reduce child mortality, which includes neonatal mortality, have been successful at reducing under-five deaths by thirty-five percent since 1990.[35] However, these gains have not been as successful for the first month of life, which now accounts for forty percent of all child deaths under five years.[35]

Neonatal mortality is caused, to a large extent, by factors associated with labor and delivery, including prematurity, infections, and birth asphyxia (Figure 3).

Millennium Development Goal 4a aimed to reduce child mortality by two thirds between 1990 and 2015.[35] Worldwide efforts to reduce under-five mortality have included reductions in neonatal deaths, though they did not specifically address fetal death prior to delivery (stillbirth). After the development and introduction of the Millennium Development Goal 4, worldwide reductions in child death followed. However, MDG 4 was not accomplished in many countries. Effective interventions to reduce child mortality, such as the Integrated Management of Child Illnesses program, were not systematically implemented in the countries needing them most, due to problems with implementation.[36]

Child mortality has fallen much faster in children ages two months to five years than in infants and neonates. Many child mortality programs have focused on efforts to reduce child mortality in ways that have not lowered infant and neonatal mortality, an important component of under-five deaths. Many programs to reduce child mortality have focused on vaccine-preventable diseases, diarrhea, and malaria, which are unlikely to reduce deaths (other than neonatal tetanus) in the neonatal period.[34] Deaths in the neonatal period have not declined at the same pace as deaths in older children, and now make up forty percent of all child mortality.

Figure 3. Causes of deaths among children under 5 years, 2013



Source: World Health Organization. Global Health Observatory: Causes of child mortality. (2014). at <http://www.who.int/gho/child_health/mortality/causes/en/>

Deaths in the neonatal period are closely tied to labor and delivery complications, and as such are less sensitive to programs targeting vaccine-preventable disease or diarrhea, and more sensitive to the treatment of maternal complications and access to obstetric care. Moreover, recommendations for postpartum care of the woman also include continued surveillance of the infant. Both fetal and neonatal mortality are closely tied to the appropriate and timely identification and treatment of maternal complications.[34] As such, reductions in under-five mortality for the Millennium Development Goal 4 also depended on strategies to address maternal morbidities and mortality, and provision of appropriate emergency services.

Perinatal mortality: Stillbirth

The World Health Organization defines stillbirth as the death of the fetus after twenty-eight weeks completed gestation, and before delivery. Worldwide, there are about 2.6 million stillbirths per year, ninety-eight percent of which occur in the developing world.[37] A recent review found a reduction in the worldwide incidence of stillbirth of 400,000 stillbirths per year since 2000. Along with neonatal death, stillbirth has recently become a larger priority in maternal and child health research, as evidenced by a 2011 series in the medical journal *The Lancet*.

Unlike neonatal mortality, published national data on the causes of stillbirth are generally unavailable. There is no consensus in the literature on how to classify the causes of stillbirth, and multiple categorization tools exist.[38] Some classification systems were developed for high-income settings and are not useful in low-income countries. Therefore, limited data is available on the worldwide causes of stillbirth.[38] Additionally, lack of resources for post-mortem investigation in low-income settings may create biases in reported causes of stillbirth. For instance, infection is listed as a cause of stillbirth less frequently in low-income settings than high-income settings, though this may reflect detection bias.[38]

Despite the challenges in attributing stillbirth, maternal hypertensive disorders are clearly a major cause.[38] A recent review of almost 8,000 pregnancies in six developing countries found hypertensive disorders to be the second leading cause of stillbirth.[39] Causes of death in this review were similar between the fetal death and early-neonatal death groups.

Stillbirth and early neonatal death are closely linked, as the precursor factors for both are similar.[40] In fact, there are very similar numbers of stillbirths and neonatal deaths worldwide, almost three million per year.[34]

Emergency Obstetric and Neonatal Care

A key component to reducing maternal and perinatal mortality is emergency obstetric and neonatal care (EmONC). Most women in low-resource countries deliver their infants at home. If complications arise during the pregnancy or delivery, women and their infants need timely access to a series of medical interventions to prevent serious morbidities and mortality.

The "E" in EmONC has been defined as either "essential" or "emergency" care; "Emergency Obstetric and Neonatal Care" will be used in this paper. The WHO defines two types of emergency obstetric case (EmONC): basic emergency obstetric and newborn care (BEmONC) and comprehensive emergency obstetric and newborn care (CEmONC) (Table 1).[41] Current recommendations indicate the need for at least four BEmONC facilities, and one CEmONC facility, per 500,000 population.[41] EmONC facilities are identified based on their performance of signal functions, such as administration of intravenous antibiotics for BEmONC facilities, or performing cesarean section for CEmONC facilities. The WHO also states that BEmONC and CEmONC facilities should be distributed geographically, though there is no specific indicator. There continues to be some discussion in the literature about the appropriate indicators of effective coverage of EmONC.[42]

Table 1. Signal Functions of Basic and Comprehensive Emergency Obstetric Care

Basic Emergency Obstetric and Neonatal Care (BEmONC) Functions	**Comprehensive Emergency Obstetric and Neonatal Care (CEmONC) Functions**
1. Administer parenteral antibiotics	All BEmONC functions 1-7, plus
2. Administer uterotonic drugs (i.e. parenteral oxytocin)	8. Perform surgery (e.g. caesarean section)
3. Administer parenteral anticonvulsants for preeclampsia and eclampsia (i.e. magnesium sulfate)	9. Perform blood transfusion
4. Manual removal of the placenta	
5. Remove retained products (e.g. manual vacuum extraction, dilation and curettage)	
6. Perform assisted vaginal delivery (e.g. vacuum extraction, forceps delivery)	
7. Perform basic neonatal resuscitation (e.g. with bag and mask)	

Source: WHO, UNICEF & UNFPA. *Guidelines for Monitoring the Availability and Use of Obstetric Services*. (1997).

The evidence is clear that emergency obstetric and newborn care reduces maternal mortality. Paxton et al. (2003) published a systematic review of emergency obstetric care, which demonstrated that EmONC was a critical strategy for reduction of maternal mortality. However, it is difficult to separate out the effect of the provision of these services from another widely used metric, and Millennium Development Goal (MDG) 5a indicator, skilled attendance at delivery. Emergency obstetric care and skilled attendance necessarily complement each other. Some researchers have suggested that EmONC should have been the third indicator to judge the success of MDG 5.[43] MDG 5a was measured by reductions in the maternal mortality ratio, and the percentage of deliveries attended by skilled health personnel. However, the effectiveness of skilled health

personnel varies widely is highly related to the availability of emergency obstetrical care. The effectiveness of skilled attendants and emergency obstetric care are necessarily highly interrelated. While not an official MDG indicator, percentage of births occurring in emergency obstetric facilities was also an important indicator of progress towards reducing maternal mortality.

Manman Ak Timoun An Sante - Free Obstetrical Care Program

Haiti's maternity services are organized under the SONU program: Soins Obstetrique et Neonataux d'Urgence (Emergency Obstetrical and Neonatal Care). The SONU program was inaugurated in 2009 after an evaluation showed unequal access to emergency obstetrical and neonatal care across Haiti. Haiti has worked to establish, or improve, both SONUB (BEmONC- Basic Emergency Obstetrical and Neonatal Care) centers, as well as SONUC (CEmONC- Comprehensive Emergency Obstetrical Care) centers. To date forty-nine SONU centers have been rehabilitated. However, Haitian government reports indicate that very few of these centers actually meet standard criteria.[12]

From 2011 to 2013, Haiti was the beneficiary of a major donor initiative to improve access to facility based delivery and emergency obstetrical care, with the goal of reducing maternal and infant mortality. The "Manman Ak Timoun An Sante" (Healthy Mothers and Children) Program was financed by the Canadian Government, and implemented by the Ministry of Public Health and Population, and the Pan American Health Organization.[44] This was the continuation and expansion of an earlier program, established after the 2010 earthquake, called the Free Obstetrical Care program. This

program offered free obstetrical care to women and infants in many public hospitals around Haiti. The funds from the program were used to provide a standard package of essential services to pregnant women, including emergency services.[45] Given chronic budget shortfalls in the MSPP, this financing ensured that women arriving to deliver would not be asked to purchase their own medications, or to pay bribes to staff not receiving their salaries.

The Manman Ak Timoun An Sante program was successful in attracting patients to public hospitals.[12] This program lowered financial barriers to care, and improved the quality of care that was offered. Although no published literature yet exists to document the public health impact of this program, anecdotally, many local providers of maternal and child health care noted a large increase in patient numbers to public hospitals supported by the program.[14]

Unfortunately, the Manman Ak Timoun An Sante program was initially funded for only two years. The program managed to extend its funding for an extra six months, but eventually stopped funding activities at the end of 2013. Hospitals that had been supported were again in the position of struggling to find funding to treat patients. Reports from the national maternity hospital stated that the doctors and residents were buying patient medications on credit in local pharmacies, and then attempting to recover some fees from patients.[14] Other hospitals reported a sharp drop in deliveries and cesarean sections, as patients were again being asked to purchase medications and supplies to cover their care.[14]

With the end of the free obstetrical care program, the situation for Haitian pregnant women may be more risky than at any time since the 2010 earthquake. Poor women are the group most likely affected by the end of this program. With most Haitian people living on less than one dollar per day, poor women may be less able to access services that now require significant user fees.

Preeclampsia and Eclampsia

Preeclampsia and eclampsia are leading causes of maternal mortality. Despite decades of intensive research, the understanding of the pathophysiology and causal mechanisms of this deadly disorder are still incomplete.[46] Preeclampsia is one of the hypertensive disorders of pregnancy. If left untreated, it can progress to eclampsia, characterized by generalized seizures, which can lead to serious morbidities and mortality. Preeclampsia is also characterized by multisystem dysfunction, including liver and kidney abnormalities.

To be diagnosed with preeclampsia, a woman will have both hypertension (persistently elevated diastolic blood pressure >90 mmHg) plus significant proteinuria (>0.3g/24 hours) develop during the second half of pregnancy.[47] In addition to high blood pressure and proteinuria, laboratory findings such as elevated liver enzymes may also be present. There is some evidence that preeclampsia and eclampsia may have different underlying pathophysiology in high-income versus low-income countries.[48] Risk factors for developing preeclampsia include extremes of maternal age (women over forty), first pregnancy, multiple gestation, diabetes, personal history of preeclampsia, and chronic hypertension.[46]

The Latin America and Caribbean region (LAC), which includes Haiti, has the highest rates of maternal mortality of any region due to hypertensive disorders including preeclampsia (Table 2).[49] Almost one quarter (22%) of deaths in LAC are due to hypertensive disorders of pregnancy.[50] However, one large cohort study of pregnant women in LAC found a prevalence of preeclampsia and eclampsia of 5%, about the same as worldwide prevalence estimates. [49,51] Risk factors for preeclampsia in this population were similar to those found in other studies. Other researchers also found differences in diet[52] and calcium intake[53] to explain higher incidences of preeclampsia.

It is unclear why the Latin American and Caribbean region has higher rates of death from preeclampsia, if rates of preeclampsia are about the same as other regions. Little data is available regarding how the diagnosis and treatment of preeclampsia in this region may differ from other regions. However, some studies have postulated specific indicators of public health system effectiveness[54] to explain differences in mortality from preeclampsia, including poor antenatal care quality, lack of access to hospital care, and lack of properly trained staff.

Despite the fact that the LAC region seems particularly at risk for maternal mortality due to hypertensive disorders, the quality of the research about hypertensive disorders in the region is lacking. A review of the literature by Peña (2012) found limited high-quality evidence about hypertension in LAC. This paper came a decade after a previous study by Ordúñez (2001) also noted the poor quality of the research investigating hypertension in LAC.

Table 2. Distribution of Causes of Maternal Death by Region

	Abortion		Embolism		Haemorrhage		Hypertension		Sepsis		Other direct causes		Indirect causes	
	N	% (95% UI)	N	% (95% UI)	N	% (95% UI)	N	% (95% UI)	N	% (95% UI)	N	% (95% UI)	N	% (95% UI)
Worldwide	193 000	7·9% (4·7–13·2)	78 000	3·2% (1·8–5·5)	661 000	27·1% (19·9–36·2)	343 000	14·0% (11·1–17·4)	261 000	10·7% (5·9–18·6)	235 000	9·6% (6·5–14·3)	672 000	27·5% (19·7–37·5)
Developed regions	1100	7·5% (5·7–11·6)	2000	13·8% (10·1–22·0)	2400	16·3 (11·1–24·6)	1900	12·9% (10·0–16·8)	690	4·7% (2·4–11·1)	2900	20·0% (16·6–27·5)	3600	24·7% (19·5–33·9)
Developing regions	192 000	7·9% (4·7–13·2)	76 000	3·1% (1·7–5·4)	659 000	27·1% (19·9–36·4)	341 000	14·0% (11·1–17·4)	260 000	10·7% (5·9–18·7)	232 000	9·6% (6·4–14·3)	668 000	27·5% (19·7–37·6)
Northern Africa	490	2·2% (0·9–4·9)	720	3·2% (0·9–8·9)	8300	36·9% (24·1–51·6)	3800	16·9% (11·9–22·9)	1300	5·8% (2·3–12·9)	3800	17·1% (7·7–30·8)	4000	18·0% (9·5–30·2)
Sub-Saharan Africa	125 000	9·6% (5·1–17·2)	27 000	2·1% (0·8–4·5)	321 000	24·5% (16·9–34·1)	209 000	16·0% (11·7–21)	134 000	10·3% (5·5–18·5)	119 000	9·0% (5·1–15·7)	375 000	28·6% (19·9–40·3)
Eastern Asia	420	0·8% (0·2–2·0)	6500	11·5% (1·6–40·6)	20 000	35·8% (10·9–68·2)	5900	10·4% (3·9–20·2)	1500	2·6% (0·4–9·7)	8000	14·1% (2·0–51·3)	14 000	24·9% (6·4–58·8)
Southern Asia	47 000	5·9% (1·5–17·3)	17 000	2·2% (0·5–6·8)	238 000	30·3% (14·0–54·8)	80 000	10·3% (5·8–16·6)	107 000	13·7% (3·3–35·9)	65 000	8·3% (3·3–17·7)	229 000	29·3% (12·2–55·1)
Southeastern Asia	11 000	7·4% (2·8–18·4)	18 000	12·1% (3·2–33·4)	44 000	29·9% (15·2–51·3)	21 000	14·5% (8·4–22·7)	8100	5·5% (1·8–15·0)	20 000	13·8% (5·6–31·2)	25 000	16·8% (7·8–34·2)
Western Asia	860	3·0% (1·0–7·6)	2600	9·2% (3·3–22·6)	8900	30·7% (17·4–49·1)	3900	13·4% (7·5–21·2)	1400	4·8% (1·5–13·1)	4500	15·6% (6·6–33·7)	6700	23·4% (11·3–43·1)
Caucasus and central Asia	250	4·6% (2·7–8·2)	590	10·9% (6·2–18·2)	1200	22·8% (17·2–30·3)	790	14·7% (11·6–18·3)	460	8·5% (5·7–13·6)	910	16·8% (12·6–23·2)	1200	21·8% (16·2–29·9)
Latin America and Caribbean	6900	9·9% (8·1–13·0)	2300	3·2% (2·6–4·7)	16 000	23·1% (19·7–27·8)	15 000	22·1% (19·9–24·6)	5800	8·3% (5·6–12·5)	10 000	14·8% (11·7–19·4)	13 000	18·5% (15·6–22·6)
Oceania	290	7·1% (1·2–22·9)	610	14·8% (1·9–47·6)	1200	29·5% (8·5–61·7)	560	13·8% (4·9–25·8)	200	5·0% (0·6–18·5)	510	12·4% (2·3–38·7)	710	17·4% (4·7–44·3)

Data shown are the estimated proportion of cause of death (%) with 95% uncertainty interval (95% UI).

Source: Say, L. *et al.* Global causes of maternal death: a WHO systematic analysis. *Lancet Glob. Heal.* **2,** e323–e333 (2014).

Perinatal Mortality, Preeclampsia and Eclampsia

There are both maternal and infant consequences of preeclampsia and eclampsia. Hypertensive disorders, including preeclampsia and eclampsia, are also the second leading cause of perinatal mortality worldwide, second only to spontaneous preterm delivery,[39] causing one quarter of all stillbirths and neonatal deaths in developing countries.[55] Several fetal problems are associated with maternal hypertensive disorders, including stillbirth, intrauterine growth restriction (IUGR), hematologic problems including thrombocytopenia (low platelet count), neutropenia (low white blood cell count), broncho-pulmonary dysplasia (abnormal development of lung tissue), neurodevelopmental changes, and increased risk for some adult-onset diseases such as diabetes and cardiovascular disease.[56] Conversely, there are some conflicting reports of neuro-protective effects of preeclampsia for preterm infants, but there is no scientific consensus.[56] The pathophysiology underlying many of these fetal risks is decreased blood flow to the fetus through the placenta.[57]

Delivery of the infant and placenta is the only treatment for maternal preeclampsia, and is necessary to prevent maternal morbidity and mortality. However, when preeclampsia develops before the pregnancy is full term (37 weeks gestation), the treatment of preeclampsia can result in premature, often low birth weight, infants. Prematurity and low birth weight are both risk factors for infant mortality. However, given restrictions in placental blood flow, there are also risks to the fetus if delivery is not completed. Management of preeclampsia attempts to balance the risks to women from

continuing a pregnancy, with those to the fetus, of both hypoxia in utero or prematurity if delivery is done.[56]

Treatment of Preeclampsia and Eclampsia

Once a pregnant woman with preeclampsia arrives at a medical facility, there are a number of clinical considerations in the management of her illness. Among other factors, the medical management of pregnant women with preeclampsia depends on the context in which she lives. A pregnant woman with preeclampsia in a high-income setting may have intensive clinical or laboratory monitoring of herself and the fetus, or consultations with neonatologists and maternal-fetal medicine specialists. Women in low-income settings have access to few of those resources, and a much higher risk of death. However, the only cure for preeclampsia and eclampsia is delivery of the fetus and placenta.

Among the immediate steps to stabilize and prevent disease progression in a patient with preeclampsia, and while delivery is planned, is administration of magnesium sulfate. Whether in high or low-income settings, intravenous magnesium sulfate administration is the gold standard to prevent the progression of preeclampsia to eclampsia. Magnesium sulfate is an anticonvulsant, and when administered to a woman with preeclampsia, it can prevent seizure activity.[58] Administration of magnesium sulfate has also been shown to be neuro-protective for preterm infants born to preeclamptic mothers.[56] However, despite the incontrovertible evidence for magnesium sulfate administration for preeclamptic pregnant women, this medication remains difficult to access in many low-income settings.[59] One district in Nigeria made huge reductions in

maternal and perinatal mortality after the introduction of magnesium sulfate.[60]

After a woman with preeclampsia has been administered magnesium sulfate, medical providers need to decide how and when to induce labor. Although delivery will treat the mother's condition, it may put the preterm neonate at risk. Developed countries typically have advanced medical facilities in which they can closely monitor a pregnant woman with preeclampsia, and support the vital systems of premature infants. Developing countries most often do not. Even "late-preterm" infants who are born just before term have a much higher rate of mortality in developing countries.[39] Preeclampsia and eclampsia cause many of the preterm deliveries at the MSF hospital in Port au Prince, leading to high numbers of low birth weight newborns, and high rates of neonatal death.

For women whose preeclampsia has progressed to eclampsia, medical management includes timely delivery of the infant, either by cesarean section or vaginally.[61] Other medical priorities include preventing injury to the woman during convulsions, preventing further convulsions with magnesium sulfate, and lowering blood pressure to safe levels with antihypertensive medications. Severe clinical consequences of eclampsia, including coma, may necessitate the need for intensive monitoring and vital system stabilization. Many low-income settings may not have the human resource or infrastructure capacity for these intensive care measures. There is a much higher case fatality rate due to eclampsia in low-income versus high-income countries.[62]

Maternal and Perinatal Mortality in Haiti

The management of pregnancy complications like preeclampsia is but one of the challenges facing the Haitian health system. The Government of Haiti, in collaboration

with the UN Development Program (UNDP), released a document in 2013 outlining the country's progress towards achieving the Millennium Development Goals: “Haiti: A New Look”.[12] This document describes recent data about Haiti's progress towards reduction in child and maternal mortality, among other goals.

The report notes a new low in the maternal mortality ratio for Haiti, at 157 deaths per 100,000 live births for 2013. The Haitian MSPP reported this maternal mortality ratio, based on reported maternal deaths from facility deliveries in 2013. However, this rate is stated to be incomplete, as it only encompasses maternal deaths that were reported to authorities.[12] Given the large majority of women who deliver at home in Haiti, this rate is likely extremely unreliable. Interestingly, the report also notes that for the very same year of data, a United Nations interagency group estimated a maternal mortality ratio of 380/100,000 live births, more than double the MSPP figure.[12]

Using either estimate, Haiti's maternal mortality rate has dropped significantly from the 1990 rate of 670 deaths/100,000 live births. Part of this reduction is likely due to the increased percentage of deliveries assisted by a trained health professional, up from 20% in 1995 to 37% in 2012.[12] This report directly credits the Free Obstetric Care program, which spurred large increases in deliveries in participating facilities.

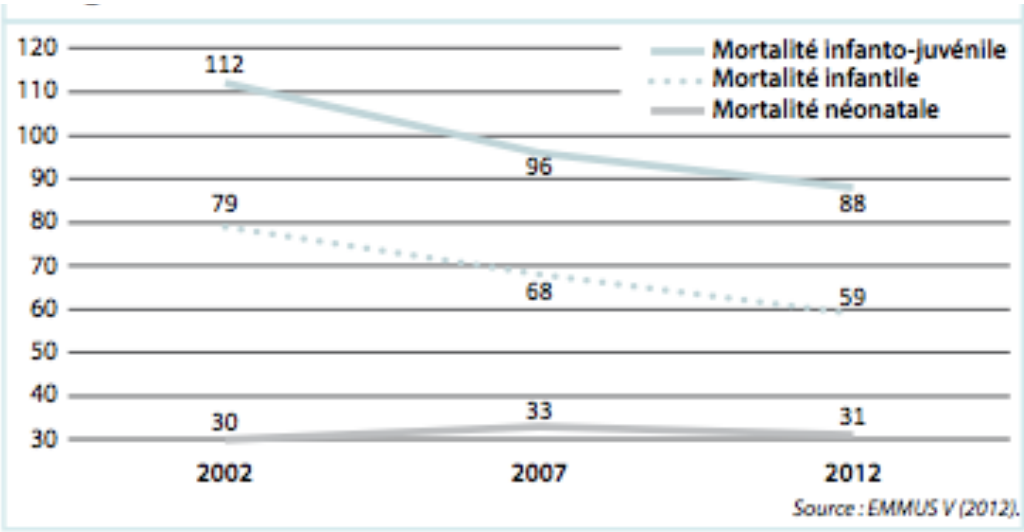
Progress towards reducing maternal mortality in Haiti is hindered by a number of factors. The Government of Haiti/UNDP report places emphasis on the lack of human resource capacity, specifically the small numbers of midwives in Haiti. Haiti is far from the goal of one midwife per 5,000 people, with only one midwife per 50,000 people. The United Nations Population Fund's State of the World's Midwifery Report highlight the

exodus of Haitian health personnel to other countries.[11] Despite a focus on rehabilitating obstetric facilities in Haiti, the UNDP report states that only sixty percent of obstetric facilities have the essential obstetric medications. Aside from health system functioning, the low rates of contraceptive usage, and high rates of teen pregnancies complicate efforts to reduce maternal mortality.[12]

The government/UNDP report states that Haiti's infant mortality rate dropped from 100 to 59 deaths per 1,000 live births.[12] However, like many countries around the world, much more progress was made in reductions in the post-neonatal period (2 months to 1 year of age). Seventy-five percent of Haiti's infant deaths occur in the first six days of life, like most developing countries. The report states that the neonatal mortality rate actually rose slightly between 1990 and 2012 (Figure 4). The report notes the difficulty of addressing neonatal mortality, when a large majority of deliveries still occur at home. Opportunities for improvements in neonatal care, including neonatal resuscitation, will affect a minority of infants in need.[12]

Haiti's infant mortality rate is much higher in urban areas than in rural areas. The infant mortality rate in Port au Prince is 81 deaths/1,000 live births versus 58/1,000 in rural areas, while internally displaced person (IDP) camps within the metro area had an especially high rate, at 124/1,000.[12] Mortality rates were higher for infants of women without educational instruction, as well as for infants in poor families.

Figure 4. Child Mortality in Haiti from 2002 to 2012, Data from DHS Haiti 2012



Source: United Nations Development Program. *Millennium Development Goals, Report 2013: Haiti*. (2014).

It is unclear why Haiti's infant mortality rate is higher in the area of the country with the highest percentage of facility-based delivery. The Port au Prince area has two and a half times more facility-based deliveries than rural areas of Haiti, but also, according to this report, the highest neonatal mortality rate.[12] Reporting bias may be influencing these figures, as infants that die after delivery at home are less likely to be reported to authorities. However, it is not clear if there are also particular risks to neonates in Port au Prince—either from the environment itself, or related to the care they receive in the facilities where they are born.

Higher rates of infant mortality in Port au Prince speak to the specific, contextual issues surrounding pregnancy in this city. There is no published evidence that describes the particular risks to infants and neonates in Port au Prince, or how that differs from their rural counterparts. However, based on the literature from other settings, higher rates

of infant mortality in this population are likely affected by lack of or delayed access to emergency obstetric care.

Médecins Sans Frontières (MSF) in Haiti

Médecins Sans Frontières (MSF), or Doctors Without Borders as the organization is known in English, is a non-governmental organization providing maternal and neonatal care in Haiti. MSF was established in France in 1971. MSF's mission is "to provide medical assistance to populations in distress, to victims of natural or man-made disasters and to victims of armed conflict. They do so irrespective of race, religion, creed or political convictions."[63] MSF's principles are based on medical ethics, independence, neutrality, and impartiality. MSF was originally founded by a group of doctors and journalists with the explicit goal of medical care in conjunction with bearing witness to extreme acts of violence. MSF is a worldwide movement comprised of twenty-four partner sections, and runs projects in seventy countries worldwide.[63]

In line with its independence, MSF does not typically apply for donor funding, and does not accept most government funding of its projects. Most of the organization's billion-dollar annual budget comes from individual donations, allowing MSF to respond where and how they determine, regardless of other actors or donor priorities. To preserve this independence, MSF also does not typically partner with other non-governmental organizations or governments. MSF responds to humanitarian emergencies based on the organization's evaluation of needs. Programs are typically designed to reduce mortality in a specific population at risk. MSF has begun to focus more on health program in urban settings, and has several programs in Latin America responding to urban violence.[64] MSF

also works to reduce maternal deaths in many countries with high maternal mortality.[65]

MSF has worked in Haiti since 1991, when a hospital rehabilitation project was started in the northeast of Haiti. In 2013, MSF employed more than 2,000 people in Haiti. Of those employees, the majority were Haitian staff. There are a number of MSF projects throughout Haiti, and the total budget for the organization in 2013 was more than 30 million euros (about 33 million US Dollars).[66] MSF's projects in Haiti focus on specialized hospital-based health care, as well as continued emergency treatment of cholera. MSF runs several hospitals in Port au Prince, including an orthopedic emergency hospital, a burns hospital, and an obstetric emergency hospital.

MSF has run obstetric hospitals in Port au Prince since 2006 at the Jude Anne hospital. This was followed by introduction of admission criteria to focus on high-risk deliveries when activities were moved to the Solidarité hospital that was later damaged in the January 2010 earthquake. Post-earthquake MSF temporarily supported the state maternity hospital until the opening of the current structure in March 2011. The Centre de Référence des Urgences Obstétricale (CRUO, Emergency Obstetric Referral Hospital) is a unique obstetrical structure for MSF as it deals mainly with obstetrical emergencies (Figure 5). The aim of the MSF CRUO hospital is to reduce maternal mortality in Port au Prince.

Figure 5. Postpartum ward at CRUO

Source: Medecins Sans Frontieres Canada. Haiti: Kangaroo Care - Simple and effective support for premature babies. at <http://www.msf.ca/en/article/haiti-kangaroo-care-simple-and-effective-support-premature-babies>

CRUO is designed as a referral hospital, which accepts only women with a specified list of obstetric complications. Women can be referred to CRUO from MSPP or private hospitals that may not have the resources to appropriately treat some obstetric complications, as well as from other NGO structures that focus on normal deliveries. Some women are admitted directly without referral, if they meet the admission criteria. The hospital is meeting the need for emergency obstetric care in the city, which MSF deems insufficient to prevent many cases of maternal mortality.

CRUO admits about 590 women per month, of which about 420 deliver. In addition to a large percentage of women with hypertensive disorders of pregnancy,

CRUO also serves women with obstructed labor, antepartum or postpartum hemorrhage, infections during labor, fetal distress in labor, post-abortion care and post-partum emergencies. A large percentage of admissions (25% in 2013) are for eclampsia and preeclampsia. Additionally, CRUO also admits some women with uncomplicated pregnancies who are imminently delivering when they arrive at the structure. These women with no known complications of pregnancy represent about twenty percent of admissions.

CRUO also includes a neonatology unit for infants born at the hospital. The neonatal admission rate is high with a 2013 average of 182 monthly admissions. On average fifty-five percent of neonatal admissions are low birth weight (less than 2.5 kg) and almost half (46%) of admissions are preterm (< 36 weeks gestation). Many of these small infants are born to mothers with preeclampsia. They are at risk for higher rates of complications after delivery.

The MSF CRUO hospital remains one of the only options for free obstetrical care in Port au Prince. However, as a referral hospital, CRUO also depends on a functioning referral system from other hospitals. Are women able to access CRUO in a timely fashion when problems arise? What are the delays that women face?

Chapter 3: Literature Review

Conceptual Model - The Three Delays

Women in Haiti suffer from the worst maternal mortality risk in the Western Hemisphere. High rates of preeclampsia and eclampsia, combined with a weak public health system and high rates of home deliveries make pregnancy dangerous for many women. As seen at the Médecins Sans Frontières (MSF) hospital in the case of Marie, the 16 year-old who died from eclampsia described in Chapter one, timely access to emergency care when complications arise is key to reducing maternal and perinatal mortality. Marie is but one of the many pregnant women who die of preventable causes in Haiti today. Organizations like MSF, as well as the Haitian Ministry of Public Health and Population (MSPP), seek to prevent these deaths through the provision of emergency obstetrical care. Understanding the causes of these needless deaths is important to providing effective programming to prevent them.

One of the most widely used and useful concepts for understanding the causes of maternal mortality is the Three Delays model, first described in 1994 by Thaddeus and Maine in their paper "Too Far to Walk: Maternal Mortality in Context".[67] In this paper, they examine the factors that lengthen the time between the onset of an obstetric complication, and its successful treatment at a medical facility, with an aim to develop more effective programs to combat maternal mortality.

Most complications of pregnancy, when treated quickly and effectively, are not life threatening. A postpartum hemorrhage can be effectively managed by a range of medical and surgical options, and rarely leads to death in a modern healthcare system.

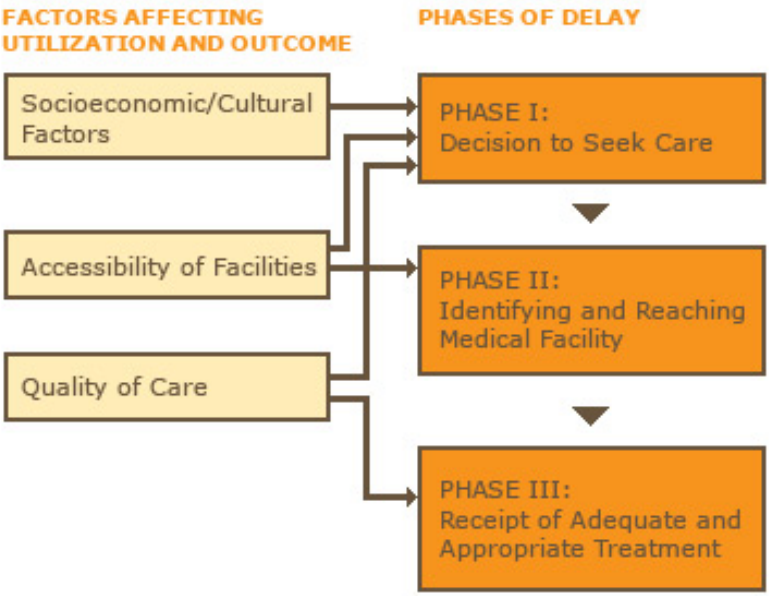
However, in those countries where access to quality medical care is limited, these complications that are routinely managed in wealthy countries are not managed in time. This delay to treat complications leads to much higher rates of maternal and infant mortality in many poor countries around the world.

In many low-income countries including Haiti, the majority of women deliver their infants at home. Increasing the percentage of women who deliver in a health facility is a major focus of worldwide efforts to reduce maternal mortality. However, until the pervasive issues of human resources and infrastructure are improved, many women will continue to deliver at home in low-income countries. Most obstetric complications have no warning sign.[68] Given this, antepartum screening is not an effective tool to identify most women who will have a complication during labor. Rather than identifying women at risk for birth complications, the World Health Organization recommends "focused antenatal care" to deliver a range of interventions aimed at reducing risks for morbidity and mortality, including iron supplementation to prevent anemia, and tetanus toxoid administration to prevent neonatal tetanus.[69] However, during the birth process, women experiencing a complication of pregnancy at home have to make the decision to seek care, and arrive at the hospital in time to prevent maternal and neonatal mortality.

Thaddeus and Maine describe three delays to receive medical care after the onset of an obstetric complication (Figure 6).[67] The first delay is the time elapsed between the onset of an obstetric complication and the woman's decision to seek health care. The second delay is the time elapsed between the decision to seek care and the arrival at the emergency obstetric facility. The third delay is the time elapsed between the woman's

arrival at the health facility, and the appropriate medical management of the pregnancy complication. Each of the delays will be discussed in greater detail in the following section.

Figure 6. Conceptual Model of the Three Delays



Source: Thaddeus, S. & Maine, D. Too far to walk: maternal mortality in context. *Soc. Sci. Med.* **38,** 1091–110 (1994) cited in United Nations Population Fund. Emergency Obstetric Care. (2014). at <http://www.unfpa.org/public/mothers/pid/4385>

The First Delay

The first delay is the delay in the decision to seek care.[67] A skilled health provider does not attend most births in low-income countries. Therefore, if a complication arises, the woman must journey to find medical help. However, the woman, or her family, needs to first decide that she needs medical help and decide to leave home to seek care.

The woman, or her family, is influenced by a number of interrelated and contextual factors about when medical help is needed. The status of the woman in the

family, her ability to make decisions, or the status of women in the culture may inhibit decision-making to seek health care.[70] The woman or her family member's educational level may affect her understanding of the obstetric complication she is experiencing, and her need for health care.[71,72] The woman or her family may not be prepared for an emergency, or not have a plan for what to do.[73] Some women may have to wait for their spouse to accompany them to seek care.[73]

A number of factors related to the accessibility of quality health care can affect the first delay. The distance needed to travel to the nearest health center has been found in many contexts to favor or inhibit women's decisions to seek care.[73–78] Thaddeus and Maine (1994) describe distance as having a duel role in delaying care—first, as the distance itself as an actual obstacle, and second, as a disincentive to even leave home. In many studies, the longer the distance to care, the longer women delayed leaving home to access care. Longer distances to access care mean increased travel time, increased expense for the family, longer times away from home, and potentially increased risks of security problems. Additionally, for pregnant women in labor with obstetric complications, increasing distances also increase the risk that the woman will have to deliver on the road.

When the woman or her family believes there is a high-quality health center available, they are less likely to delay seeking care. The availability of quality health care has been found to overcome some of the barriers of distance in some settings.[79] Thaddeus and Maine, in their original article on the Three Delays, highlight the importance of accessible, quality obstetric care, for its impact on reducing all three

delays.

The cost of seeking care and receiving care may also influence the delay at home. If a woman or her family has few economic means, or if the projected costs are expected to be high, they may delay the decision. At a more fundamental level, impoverished families may have less access to health care in general, which would also affect care-seeking for emergency obstetric care.[67]

These factors affecting the first delay are contextual and interrelated. For instance, a lack of understanding of the gravity of a complication may lead to an overestimation of the barriers to seek health care. Individual characteristics, family dynamics, and cultural factors have multiple and complex interactions on women's decision to seek emergency obstetric care.

The Second Delay

The second delay is the time taken between the decision to seek medical care, and the arrival at a medical structure. As opposed to the first delay, in which distance or cost is a psychological barrier to deciding to seek care, in the second delay these issues become the obstacles to overcome.[67]

There are several issues, including transportation, infrastructure and distance that affect the second delay. The woman and her family need to find a way to travel from the home to the emergency obstetric facility. Transportation may have to be arranged if the family does not own a means of transport. Especially in rural areas, it may be difficult to arrange transport from the house to the hospital. Pregnant women suffering complications may be unable to walk to reach transport. Finding money to arrange

transport can be a major barrier.[73] On nights or weekends transport options may be more limited, leading to longer delays. In some areas, insecurity or violence may limit transport during certain times.

The referral mechanisms for women with obstetric complications may also add to delays.[73] Women who are being treated by a traditional birth attendant may be kept at home for too long prior to referral. Local health centers may not be adequately staffed, leading to further delays in referral. Health providers living in the woman's area may not be available to refer the patient when the complication arises. After finding money and arranging transport, the woman and her family must negotiate the distance to the health center.[67] Bad roads, and weather-related barriers such as swollen rivers, may inhibit travel. Conflict or violence may limit travel options and routes.

The geographic distribution of emergency obstetric facilities is a key factor in their accessibility to women. Many studies have noted the over-representation of hospitals in urban areas. In rural areas, where population density is by definition lower, distances to hospitals are often much longer. However, even in urban areas, women can have difficulty accessing emergency obstetric care. A study in Nairobi, Kenya, found that women living in urban slums had to surmount many barriers to access transportation.[80] Even though women in this study lived in a major city with many hospitals, poor road infrastructure in their neighborhood, coupled with seasonal difficulties due to flooded streets, meant that women in this urban area struggled with many of the same barriers to care that are typically associated with rural living.

Transport to emergency obstetric care depends not only on the physical

availability of health structures, but also on public safety measures in place. In areas where travel after dark is dangerous, women with obstetric complications are essentially limited to daytime care seeking. Public safety problems can delay women's departure for emergency obstetric care, if they cannot leave for the hospital during the night.

In a meta-analysis of the first and second delays to care, McNamee et al. (2009) found that women's educational level, the family's economic status, and the distance to the facility were the most important predictors of the utilization of health services.[81] The first and second delays are sometimes categorized as "demand-side" delays, as they are affected by the patient's desire and ability to access care.

The Third Delay

The third delay noted by Thaddeus and Maine describes the delay in receiving appropriate treatment for the obstetric complication once the woman has arrived at the medical structure.[67] These factors can further delay the administration of appropriate emergency obstetric care, further endangering the woman and her fetus.

In low-resource settings, emergency obstetric care facilities are often not equipped or staffed appropriately. Knight, Self and Kennedy published a systematic review of factors influencing the third delay (2013). They identified thirty-two barriers to timely and appropriate care at the facility level, which they characterized into six themes: drugs and equipment, policy and guidelines, human resources, facility infrastructure, patient related, and referral related.[82] Of these, human resource problems were the most prevalent. Human resource problems include inadequate training, inadequate staffing, and lack of twenty-four-hour staffing.

Human resource shortages are a major problem throughout the developing world. In particular for obstetric care, lack of qualified obstetricians and midwives are a major barrier to reducing maternal mortality.[82] Lack of qualified health professionals means that even when a woman with an obstetric complication manages to reach a health facility, there may not be trained staff available to care for her. Moreover, inadequate training may lead to inappropriate care being given to the woman.[83]

The availability of comprehensive emergency obstetric care, which includes cesarean section, is a key component of measures to reduce maternal and perinatal mortality. The availability of these services is related in large part to health system financing. Many low-income countries have not met commitments to fund their health departments at adequate levels.[84] In these countries, providing adequate coverage of comprehensive emergency obstetric coverage may be prohibitively costly.[68] In many settings, women who manage to arrive at the obstetric facility may still face long delays to receive appropriate care.

As Thaddeus and Maine note (1994), the availability and quality of medical care affects more than the third delay. Women's understanding and perceptions of the availability and quality of medical care influence decision-making on when to leave home to seek care. As several studies have noted, women are willing to travel farther when the quality of medical care, or their perception of the quality, is high.[79] Other studies have noted that greater economic means lead to women to travel longer distances, presumably as women seek out higher quality care.[71]

Twenty Years of the Three Delays

Since Thaddeus and Maine defined the Three Delays concept, it has been used throughout the world to investigate the causes of maternal mortality, and to plan programmatic responses. The Three Delays model has been used in high maternal mortality burden, low-income contexts as diverse as Papua New Guinea[85], Nepal[70], Brazil[86], and Liberia[87], as well as many others. Twenty years after its publication, it remains the predominant conceptual model for maternal mortality in low-income countries.

There have been some challenges to, and reworking of, the Three Delays model. Several authors have noted that the Three Delays model was designed to cover only emergency care, but that it can also encompass preventive services and normal birth.[75,88,89] Gabrysch and Campbell expanded the conceptual model to include both emergency and preventive care-seeking. They note that similar factors may be involved in both, though their importance may differ in their impact on each type of delay.[75] The Three Delays can also be relevant for access to normal delivery.[89] However, the relative importance of delays to care for preventive services or normal delivery has not been evaluated for its effect on maternal morbidity or mortality. While delays and barriers to access preventive care are important to understand, they are unlikely to have the same impact on maternal and neonatal mortality as delays to emergency care.

Other authors have questioned the usefulness of the Three Delays model for prospective, program-oriented solutions.[88] They suggest that the model is most useful as a retrospective tool to review causes of mortality, and that there are no specific responses

for surveillance efforts or program responses. However, it is clear from the literature that the Three Delays model has, in fact, been used by many programs to plan programs to reduce specific delays to care.[90,91]

Other critiques of the Three Delays model have focused on the power dynamics and structural issues inherent in maternal deaths. Iyer, Sen and Sreevastha offer one challenge to the Three Delays model's focus on timeliness (2013). In their perspective, the focus on women's decision-making delays obscures the power dynamics and health system issues at play. Additionally, they state that the focus on delays can distract from the appropriateness of the actions taken, regardless of the time taken to make them.[92] D'Ambruoso, Byass and Quomariyah also expand on the Three Delays model using qualitative data from interviews with family members of women who died in pregnancy. They call attention to structural issues of access that create delays to obstetric care, stemming from and causing the systematic exclusion of poor people.[93]

Maternal "Near-Miss"

There has been a renewed interest in the Three Delays model as researchers have used the model to review not only maternal death, but also "near-miss" events.[94] A new taxonomy has recently been created by the WHO to standardize discussion of these events.[95] The WHO defines a maternal near-miss, or severe acute maternal morbidity, as "a woman who nearly died but survived a complication that occurred during pregnancy, childbirth or within 42 days of termination of pregnancy."[95] The WHO has recommended using the term "maternal near-miss" to describe these events.

However, standardization of the diagnostic criteria for maternal near-miss is less clear. The WHO recommends using criteria for organ-system dysfunction to diagnose cases of maternal near-miss. They present a list of criteria that can be used in low-resource settings that translate organ-system dysfunction into clinical criteria that can be used without advanced resources. They augment this list with laboratory and management-based criteria (Table 3).[96]

Near-miss cases share many of the same precursors as maternal deaths, but are much larger in number, so they are useful for researchers given that maternal deaths are relatively rare, and it is difficult to design a study with adequate power to identify significant predictors of maternal death. By studying maternal near-miss, researchers can increase knowledge on the causes and prevention of maternal death. Say, Lale, and Pattinson (2009) report on the usefulness of maternal near-miss. Near-miss cases can be used to monitor the quality of obstetric programs. Survivors of maternal near-miss are also uniquely placed to report on breakdowns of the public health system that may have occurred in their cases. Finally, maternal near-miss indicators can be used to compare settings, and monitor progress over time.[96] Researchers have used maternal near-miss cases to investigate delayed access to care, using the Three Delays model.[88]

Table 3. WHO Maternal Near-Miss Criteria

The WHO maternal near miss criteria: a woman presenting with any of the following life-threatening conditions and surviving a complication that occurred during pregnancy, childbirth or within 42 days of termination of pregnancy should be considered as a maternal near miss case.

Clinical criteria	
Acute cyanosis	Loss of consciousness lasting ≥12 hours[e]
Gasping[a]	Loss of consciousness AND absence of pulse/heart beat
Respiratory rate >40 or <6/min	Stroke[f]
Shock[b]	Uncontrollable fit/total paralysis[g]
Oliguria non responsive to fluids or diuretics[c]	Jaundice in the presence of pre-eclampsia[h]
Clotting failure[d]	
Laboratory-based criteria	
Oxygen saturation <90% for ≥60 minutes	pH <7.1
PaO_2/FiO_2 <200 mmHg	Lactate >5
Creatinine ≥300 μmol/l or ≥3,5 mg/dl	Acute thrombocytopenia (<50 000 platelets)
Bilirubin>100 μmol/l or > 6,0 mg/dl	Loss of consciousness AND the presence of glucose and ketoacids in urine
Management-based criteria	
Use of continuous vasoactive drugs[i]	Intubation and ventilation for ≥60 minutes not related to anaesthesia
Hysterectomy following infection or haemorrhage	Dialysis for acute renal failure
Transfusion of ≥5 units red cell transfusion	Cardio-pulmonary resuscitation (CPR)

[a] Gasping is a terminal respiratory pattern and the breath is convulsively and audibly caught.
[b] Shock is a persistent severe hypotension, defined as a systolic blood pressure <90 mmHg for ≥60 minutes with a pulse rate at least 120 despite aggressive fluid replacement (>2l).
[c] Oliguria is defined as an urinary output <30 ml/hr for 4 hours or <400 ml/24 hr.
[d] Clotting failure can be assessed by the bedside clotting test or absence of clotting from the IV site after 7–10 minutes.
[e] Loss of consciousness is a profound alteration of mental state that involves complete or near-complete lack of responsiveness to external stimuli. It is defined as a Coma Glasgow Scale <10 (moderate or severe coma). Details on the scale on the Fig. 3.
[f] Stroke is a neurological deficit of cerebrovascular cause that persists beyond 24 hours or is interrupted by death within 24 hours.
[g] Condition in which the brain is in a state of continuous seizure.
[h] Pre-eclampsia is defined as the presence of hypertension associated with proteinuria. Hypertension is defined as a blood pressure of at least 140 mmHg (systolic) or at least 90 mmHg (diastolic) on at least two occasions and at least 4–6 h apart after the 20th week of gestation in women known to be normotensive beforehand. Proteinuria is defined as excretion of 300 mg or more of protein every 24 h. If 24-h urine samples are not available, proteinuria is defined as a protein concentration of 300 mg/l or more (≥1 + on dipstick) in at least two random urine samples taken at least 4–6 h apart.
[i] For instance, continuous use of any dose of dopamine, epinephrine or norepinephrine.

Source: Say, L., Souza, J. P. & Pattinson, R. C. Maternal near miss--towards a standard tool for monitoring quality of maternal health care. *Best Pract. Res. Clin. Obstet. Gynaecol.* **23,** 287–96 (2009).

Conceptualizing Perinatal Mortality with the Three Delays Model

Many of the same complications of pregnancy that cause maternal mortality, such as infections, preeclampsia or prolonged labor, also cause perinatal mortality.[97] The solution to these problems is also the same: facility based delivery with a skilled attendant. For deliveries starting at home, access to emergency obstetric care is key.

The Three Delays model has also been used to conceptualize stillbirth and early neonatal mortality, the components of perinatal mortality.[98,99] Stillbirth is directly related to the delay to appropriate treatment of maternal complications. Several researchers have discussed the link between stillbirth and delayed access to emergency obstetrical care. One group of researchers published a series of articles showing that maternal delays to accessing appropriate obstetrical care was a critical risk factor for stillbirth.[100] A retrospective review of maternal near miss in Afghanistan found an association between delay to care and stillbirth.[101] A qualitative study of perinatal death in rural Gambia found that many of delays reported by participants increased their risk for stillbirth.[102] Research in India has also noted the link between stillbirth and delays to appropriate emergency obstetric care.[103]

Furthermore, treatment of neonatal complications can be hindered by delays in much the same way that delays to recognize the need for care, access care, and receive care hinder appropriate treatment of obstetric complications. In a direct corollary to maternal deaths, infant deaths are rare when delivery occurs in well-equipped health facilities and attended by skilled providers.[100] Infant problems after delivery are a leading cause of neonatal mortality, as two thirds of all neonatal deaths occur in the first week of life, and of these deaths, two thirds occur in the first twenty-four hours.[104]

Some researchers have focused on the Three Delays model to conceptualize neonatal deaths. As with maternal mortality, the vast majority of infants faced with life-threatening complications can be treated if the appropriate medications, supplies and human resources are available.[105] Wall et al. note that delays to appropriate emergency

care to reduce perinatal mortality are very time-sensitive, as every minute of delay can worsen fetal injury.[57]

Preeclampsia in Haiti

Among the Latin America and Caribbean region (LAC), Haiti has some of the worst health indicators, including maternal and neonatal mortality.[106,107] Preeclampsia is estimated to be the leading cause of maternal death in the Latin America and Caribbean region.[49] Preeclampsia and eclampsia are also major causes of death in Haiti. Despite the lack of comprehensive understanding of the causes of preeclampsia, the risk for this disorder is clearly higher in individuals with a history of chronic hypertension. Haiti has an extremely high prevalence of hypertension, with less than twenty-five percent of adults over forty having normal blood pressure.[108] Programs aiming to reduce maternal and perinatal mortality in Haiti, like that of MSF, treat many obstetric emergencies related to preeclampsia and eclampsia.[109]

The Government of Haiti published a report in 2013 that stated that preeclampsia was a major cause of maternal death.[12] Unfortunately, no data or research was cited for this claim. However, this report, which was written in conjunction with the United Nations Development Program, speaks clearly to the magnitude of the problem of preeclampsia in Haiti.

Only two published studies have evaluated the prevalence of preeclampsia in Haiti. In both of these studies, retrospective diagnosis data was evaluated for women delivering at the Albert Schweitzer Hospital, a highly respected non-governmental facility in a rural area of Haiti. In the first study, which evaluated 3,000 births,

preeclampsia or eclampsia affected 18% of births.[110] In the second study, which evaluated more than 1,700 births, preeclampsia or eclampsia affected 17% of births.[111] It is likely that selection bias affected the prevalence of preeclampsia and eclampsia in these studies, leading to an over-estimate of the prevalence of preeclampsia. In rural areas of Haiti, like the location of Albert Schweitzer Hospital, the majority of women continue to deliver at home. It is likely that women with complications of pregnancy, like preeclampsia or eclampsia, were more likely to seek medical care, at the hospital so the estimates may be over-estimates. Nonetheless, as the only two published estimates of these disorders among Haitian pregnant women, these studies points to the potentially large number of cases in the country.

Other Pregnancy Complications in Haiti

One of the best resources for data on pregnant women in Haiti is the Demographic and Health Survey (DHS), a survey of households and women conducted by ICF International periodically in many low and middle income countries worldwide. The DHS provides the only recent population-level data about pregnancy in Haiti (2012). However, the DHS does not investigate specific complications of pregnancy like preeclampsia, although it does report on vaccine-preventable illness like tetanus. The DHS data shows that a large majority (90%) of Haitian pregnant women had received antenatal care for their last pregnancy, and more than two thirds had received the recommended four visits (67%). However, a little more than one third of women delivered their last infant in a health center (36%), or with a skilled birthing attendant (37%). Low rates of facility-based delivery and skilled attendance at birth are noted risk

factors for maternal and infant mortality. With most women delivering at home, access to emergency obstetric care in the case of complications is crucial for avoiding maternal and infant death.

The DHS does not report on the incidence of pregnancy complications such as preeclampsia. Very little other literature describes specific complications of pregnancy facing Haitian women, including the prevalence of preeclampsia. The limited research that is available reports high rates of preeclampsia (as described above), heart failure, sexually transmitted infections, and intimate partner violence in Haitian pregnant women.

Several articles have described Haitian pregnant women's risk factors for HIV and other sexually transmitted infections (STI's). The Caribbean region has the highest prevalence of HIV infection outside of Africa, and in this region, Haiti has the highest prevalence.[112] The current prevalence in Haiti is estimated at two percent[10], with women infected at twice the rate of men.[113] Prevention of maternal to child transmission (PMTCT) has been a major focus of HIV/AIDS and maternal health care activities. PEPFAR, the President's Emergency Plan For AIDS Relief funds PMTCT activities at public maternity hospitals throughout Haiti.[114] GHESKIO, the Groupe Haïtien d'Étude du Sarcome de Kaposi et des Infections Opportunistes (Haitian Group for the Study of Kaposi's Sarcoma and Opportunist Infections), is a Haitian non-governmental organization dedicated to reducing the HIV/AIDS epidemic in Haiti. Since 1999, GHESKIO has been providing PMTCT services to pregnant women in Port au Prince, reducing transmission rate among their population from 27% to 9% in the early years of the program.[115] In 2013, more than 3,500 Haitian pregnant women throughout the

country were started on antiretroviral therapy during their pregnancy, and the transmission rate from mother to child was seven percent.[116]

Haitian women are also at risk for other types of infectious diseases during pregnancy. In particular, other sexually transmitted infections (STI's) have been documented as very prevalent in Haiti, and have been the focus of several research studies. A 1995 study by Behets et al. found that pregnant women attending an antenatal clinic in a slum of Port au Prince had very high levels of STI's. Almost half of the 996 women seen (44%) tested positive for an STI.[117] Another study found that 40% of pregnant women attending antenatal care were pregnant with at least one sexually transmitted infection.[118] Syphilis infection, which can cause severe newborn morbidity, remains a major problem among Haitian women, despite cost-effective testing and treatment measures.[119] One study found that of women tested during antenatal care, eleven percent tested positive for syphilis, which can have devastating effects on the growing fetus.[118] A number of other studies have also found significant numbers of syphilis-affected women, ranging from five to eight percent of pregnant women.[118,120,121] While the data from some of these studies on STIs are almost twenty years old, they demonstrate the risk of these infections among Haitian pregnant women. The prevalence of STIs may be lower today, given the work in Haiti to increase awareness and usage of condoms related to HIV-prevention efforts.

Magee et al. (2006) described risky sexual behaviors among expectant fathers in Haiti, helping to explain some of the high rates of sexually transmitted infections among pregnant women.[122] In this study, about 30% of the expectant fathers, who had been

referred to the study by their pregnant partner, had more than one sexual partner in the previous year. More than two thirds (68%) reported they had not used a condom in the past year. Even among the men with more than one sexual partner, the majority did not use condoms in the last year. The authors report that Haitian cultural norms include both the desire for many children and multiple sexual partners for men, both of which reduce the likelihood of condom usage. These factors also increase the risk of HIV and other sexually transmitted infections for women.

Progress has been made towards reducing, with a goal of eventually eliminating, other infectious diseases in pregnancy. Measles and rubella were targeted for eradication in Haiti, and current data indicates very high levels of immunity.[123] Cholera, introduced into Haiti after the earthquake by United Nations peacekeepers, has been declining in incidence. Cholera was also a risk for pregnant women. A study published by MSF showed an eight percent risk of intrauterine fetal death in pregnant women positive for cholera.[124]

In addition to a high prevalence of infectious diseases, Haitian women are also at risk for other complications of pregnancy. Peripartum cardiomyopathy is a deadly and poorly understood type of heart failure that affects pregnant women. Peripartum cardiomyopathy is ten times more prevalent in Haiti than in the United States.[125,126]

Violence also appears to be a major problem affecting Haitian pregnant women. The most recent Demographic and Health survey indicates that of women pregnant during the survey, six percent had experienced physical violence during that pregnancy.[3] Almost a three in ten (29%) of women had experienced emotional, physical or sexual

violence by their partner since the age of 15.[3] Small et al. (2008) describe the results of a cross-sectional survey of 200 women accessing antenatal care at rural dispensaries served by the Albert Schweitzer Hospital. They found that 44% of respondents had experienced violence in the previous six months, with 77% of those women reporting intimate partner violence. Women experiencing intimate partner violence had statistically significantly higher measures of pregnancy discomforts.[127] Additionally, another study in Haiti that examined DHS data showed a prevalence of 25% of intimate partner violence.[128] This contributed to an extremely high overall rate in the Latin America and Caribbean region, estimated as the highest in the world. These researchers identified intimate partner violence as a risk factor for poor maternal and fetal outcomes. Intimate partner violence was also associated with a higher rate of preeclampsia.[129]

One study in Haiti found that many pregnant women self-medicated during pregnancy, many with potentially harmful medications. Jules et al. (2010) found that 75% of women surveyed in the postpartum ward of a maternity hospital reported taking medication during the pregnancy. A significant percentage (13%) of women delivering had taken a medication that was potentially harmful to their fetus.[130] Most of these harmful medications were pharmaceuticals that were purchased from a pharmacy or in the market without a prescription.

While the evidence is not complete on the complications of pregnancy faced by Haitian women, the picture painted by these studies is of some serious risks to the health of both mother and child. Due to the lack of data about pregnancy complications, one researcher asked Haitian pregnant women directly about their experience of

complications of pregnancy. This study found bleeding, fever, pain and perineal lacerations were the most commonly cited complications of pregnancy.[131] Adding to these risks are the many problems associated with preeclampsia and eclampsia. Risk factors for these disorders, like chronic hypertension, can be detected during antenatal care.

Antenatal Care Utilization in Haiti

According to the most recent DHS data, pregnant women in Haiti have high rates of antenatal care utilization, and the percentage of women receiving antenatal has steadily increased over the last fifteen years. Ninety percent of women in Haiti reported receiving antenatal care during their most recent pregnancy. Of interest for this study, this percentage was slightly higher for women living in the Port au Prince area (92%).[3] However, inequalities are still present. Among women with no education, a much smaller percentage (81%) received antenatal care, versus those with secondary school education or higher (97%). The WHO recommends four visits to accomplish the evidence-based recommendations for antenatal care in low risk women. In Haiti, 78% of urban women received at least four visits, as compared to 62% in rural areas.[3]

Perhaps counter intuitively, despite high levels of antenatal care coverage, a much smaller percentage of women delivered their infants in a health center or hospital. Haiti is among a number of low income countries where antenatal care coverage is much higher than skilled attendance at birth, or facility-based birth. However, there are many factors that may hinder access to delivery care even when antenatal care access is possible. If quality of delivery services is low, or if financial barriers to accessing care

are high, women may have different motivation and ability to access delivery versus antenatal services. In Haiti, antenatal services are very low-cost or free. However, women are often asked to purchase medication and supplies for deliveries, and may also have to pay bribes to hospital staff.[14]

Postpartum complications in Haiti

Quality postpartum care is an important aspect of preventing maternal and neonatal mortality, including from preeclampsia and eclampsia. Almost half of eclamptic seizures can develop during the postpartum period.[61] Newborn care is also an essential component to postpartum care. Therefore, delayed access to care can still be an important predictor of maternal and neonatal mortality even after delivery. The DHS reported very low rates of utilization of postpartum services in Haiti, including just (39%) by women and (31%) for their infants A trained health care provider saw little more than a third of women or infants in the recommended timeframe. Not surprisingly, among women who did not deliver in a health structure, only 12% received appropriate postpartum care.

Two studies have focused specifically on needs of postpartum women in Haiti. Lathrop et al. (2011) found that in a sample of about 300 women delivering in a hospital in northern Haiti, the vast majority (98%) of women were interested in receiving contraceptive counseling before discharge, but only a very small percentage (6%) received counseling. Eighty percent of women wanted to receive a contraceptive method prior to discharge from the hospital; however, there was no mechanism for contraception provision.[132] Birth spacing and family planning is an important aspect for the prevention

of maternal mortality. Poor postpartum care in Haiti may be undermining these possibilities.

Another study of postpartum women in Haiti focused on the outcomes of HIV-positive pregnant women.[133] Of the cohort of 500 HIV-positive women who delivered at the non-governmental organization GHESKIO between 1999 and 2005, almost one quarter (22%) were lost to follow-up. Another group (25%) were not started appropriately on anti-retroviral medications according to protocol. GHESKIO is one of the most respected and effective health care organizations in Haiti; even in this setting, postpartum follow up and care for this at-risk population were limited.

Delayed Access to Health Care for Haitian Pregnant Women

Given high rates of maternal and infant mortality, and low rates of coverage to skilled birth attendance, many researchers have focused on Haitian women's access to emergency obstetric care. These access problems are compounded by high rates of preeclampsia among Haitian pregnant women. For women with complications like preeclampsia, accessing emergency obstetric care may be difficult. Haiti has a centralized, weak public health system, and the majority of doctors and hospitals are in urban areas, so women in rural areas have been assumed to have less access to health care. As such, research on access to obstetric care in Haiti has focused almost exclusively on pregnant women living in rural areas.

Barnes-Josiah (1998) published a seminal study of delayed access to emergency obstetric care in rural Haiti in 1998. In this study, cases of maternal deaths were sampled from a nationwide, prospective study of causes of maternal death. More than 10,000

pregnant women were enrolled in this prospective study. Follow-up visits identified cases of maternal death among the enrolled participants. Study personnel then conducted verbal autopsy to determine the medical cause of death, as well as a "social autopsy" to determine the non-medical circumstances surrounding the death.[74] Unfortunately, political violence and a *coup d'état* interrupted the second round of study data collection. However, the study authors were able to use the social autopsy to investigate the delays faced by these women who ultimately died.

This study found that Haitian women faced many types of delays in accessing emergency obstetrical care. All cases of death investigated were in rural areas. Eight of the twelve women delayed or did not seek care. Reasons given included distance, lack of transportation, and economic concerns. Families of two other women also reported that they did not have confidence that there would be a doctor available at the nearest health center, or that they would be referred to a further hospital. This study also found that most women died of causes that could have been treated had they received appropriate health care.[74]

The study authors report that the perception of inadequate or ineffective health care influenced the decision and delay to seek health care. "Typically, families must balance the time lost in domestic labor and child care, the costs of transportation, services, meals, bribes and fees, and the emotional stress of travel, with the dubious benefits of unproven care." (Barnes-Josiah 1998, p. 987). Of the twelve cases of maternal death investigated, six women who did arrive for care received ineffective or no treatment at all. Barnes-Josiah interprets the results of the study to make the case that the

low quality of medical care available underlay most of the cases of maternal death. While delays taken at home contributed to the deaths, these delays were often underpinned by the lack of confidence in the medical system.

Gage et al. (2006), in a secondary analysis of DHS data collected in 2000, found that increased distance to health care in rural Haiti was associated with a lower facility-based delivery, though rates of antenatal care were not affected. They also found associations between lower socioeconomic status, poor road conditions and mountainous terrain, with measures indicating low uptake of health services, including antenatal care, skilled birth attendance, and facility based delivery. [134]

Among the existing studies examining access to emergency obstetric care, none have been published on access to care for urban Haitian women. However, despite the concentration of resources in Port au Prince, almost forty percent (38%) of pregnant women choose to deliver at home.[3] These women, when faced with a pregnancy complication, like preeclampsia, may face delays and obstacles to reaching emergency obstetric care. The latest DHS survey (2012) indicated that of pregnant women living in Port au Prince, 71% had difficulty accessing health care when they had a medical problem.[3] However, no studies are available that examine these difficulties or their effects on maternal and perinatal health.

Addressing Access Problems for Pregnant Women in Haiti

Haiti, through both government-run and international efforts, has implemented various programs to reduce maternal and perinatal mortality. The MSPP has used strategic government planning to focus energy and financing on improving maternal and

child health. Specifically, the Politique Nationale de Sante (National Health Plan) has specific objectives related to improving health coverage for women and infants throughout Haiti. The MSPP has also been the recipient of donor funding for various maternal and child health initiatives, evident in the number of different programs targeting maternal and child health. The Plan Stratégique National de Sante de la Reproduction et Planification Familiale (National Strategic Plan for Reproductive Health and Family Planning) has specific objectives related to reduction of maternal mortality. Plan Stratégique National Sur la Santé Intégrale de L'Enfant en Haïti (National Strategic Plan for Integrated Child Health in Haiti) elaborates objectives for the reduction of infant and neonatal mortality. Haiti also has an integrated childhood illness program, a national vaccination program, a social insurance program, a national family planning program, the SONUB/SONUC (emergency obstetric care) program, and the now-defunct Manman Ak Timoun An Sante (Healthy Mothers and Children) program.[12]

Even with this long list of government-sponsored programs, there remain significant obstacles to accessing appropriate maternal and child health care. The Government of Haiti itself describes the lack of coherence among the various national programs listed above, each of which has its own objectives and indicators for maternal and child health.[12] Part of this may be due to the realities of donor-funded programs, which come with their own set of requirements, which the Government of Haiti may or may not be able to adjust to meet their own objectives. Additionally, lack of funding for some of the most important projects, including the rehabilitation of emergency obstetric facilities, and the free obstetric care program, are major barriers.[12]

Two studies describe non-governmental programs for pregnant women that were planned or implemented to address the issues of difficult access to health services in Haiti. Hossain et al. (2014) and Shaffer, Fryzelka and Obenhaus (2007) both implemented services to reduce delays to emergency obstetric care. Hossain et al. report on results of a survey in Northern Haiti.[135] Women in this study had very high coverage of antenatal care (94%), but only half of them (54%) delivered in a health care facility. Women reported that their decision to deliver at home was mostly due to financial barriers, unexpected labor, and convenience. These women reported that they would be willing, and they believed their families would be supportive, if they stayed in a maternity waiting home for a future pregnancy. Maternity waiting homes have been implemented around the world to address the difficulty of offering emergency obstetric care to women living in remote and rural areas.[136,137] These programs typically offer a home-like area close to the hospital where high-risk women spend the last few weeks of their pregnancy. The woman who stays at the maternity waiting home has close to immediate access to facility based delivery and emergency obstetric care at the time of delivery. There are no published reports of maternity waiting homes in Haiti.

The birthing home model implemented in the study described by Shaffer, Fryzelka and Obenhaus (2007) is a pilot program that attempted to address some of the barriers to access faced by Haitian pregnant women, although it was not a maternity waiting home. In this model, a community-based birthing home offered delivery care to low-risk women, and referrals to emergency obstetric care when needed. However, several issues limit the feasibility and acceptability of this program. This program aimed

to deliver only low-risk women at the birthing home. However, a wide number of studies have demonstrated that most complications of childbirth have no antecedent risk factors. In this birthing home pilot, in fact, they did not find any reduction in maternal mortality. Furthermore, it is unclear from the reported study whether this birthing home was equipped with the necessary supplies and medications to qualify as a Basic Emergency Obstetric and Neonatal Care center (BEmONC). If it did not, in fact, offer the basic emergency services as outlined by the World Health Organization[41], then it seems questionable that this program worked to attract deliveries to a health center that was not equipped to basic standards.

Summary: Synthesis of the literature and remaining gaps

The maternal and child health research that is available for Haiti is incomplete, despite high levels of maternal and perinatal mortality. Despite the lack of published evidence, unpublished reports and anecdotal evidence speak to the hard realities of pregnancy in urban Haiti. These difficulties are in evidence every day at the MSF hospital in Port au Prince, where women and their infants suffer and die from preventable causes.

There is evidence from the DHS, and from limited other published research, that pregnant women in Haiti face a range of health problems, for which there is limited access to emergency obstetrical care. The available research on pregnancy in Haiti paints a picture of women at risk from preeclampsia, peripartum cardiomyopathy, sexually transmitted infections, and intimate partner violence, among other issues. Data about the availability of health services to treat these problems, and others, show high levels of

coverage for antenatal care, but low facility-based delivery. There is evidence from other countries that the provision of emergency obstetric care, alongside skilled attendance at delivery, is a crucial element to reduce maternal mortality.

Pregnant women in urban Haiti face contextually-specific risks, many of which may be unknown; they may also have different obstacles to seeking care. Research in rural Haiti has found distance to be the most important factor in delayed access to emergency obstetrical care. While rural residents must navigate mountainous terrain, low coverage of emergency obstetric care, and transport obstacles, urban residents also face barriers to receive emergency obstetric care. The lived experience of women in Port au Prince differs substantially from those of their counterparts in rural areas.

Missing from the published research is evidence regarding the risks and delays faced by pregnant women in Haiti's capital city, Port au Prince. With forty-five percent of Haiti's population, the city's residents face a host of environmental, safety and health concerns that are quantitatively and qualitatively different than their rural counterparts. While some researchers have examined the barriers to emergency obstetric care faced by rural Haitian women, to this date no research has been published outlining barriers to access for urban Haitian women. Although some of the concerns of rural women may also apply to their urban counterparts, particularly financial barriers or cultural preferences for home birth, there may also be other, urban-specific concerns. Other researchers have examined the urban-specific risks for delays in emergency obstetric care[80], but this evidence does not yet exist for the Haitian context.

The Three Delays model suggests a number of factors that can cause delays to access emergency obstetric care, including distance to care, cost, women's educational level, women's status in the family, transportation, distribution of facilities, and the woman's perception of the quality of care available.[67] There is no evidence about how these factors influence urban Haitian women's access to emergency obstetric care.

Port au Prince is a crowded and traffic-congested city. How do transportation options in this city serve to either hinder or facilitate access to emergency obstetric care? Massive new slums are sprouting up on the fringes of the city. Are women who live in these locations able to access hospitals located in the center city? Some areas of Port au Prince are controlled by gangs, and are extremely dangerous, especially at night. How do women living in these areas access emergency obstetric care? These questions are specific to the Port au Prince area, though they apply to women living in many urban areas.

Though Port au Prince is the site of most major hospitals in the country, access to these hospitals may still be limited. Public hospitals, while nominally offering comprehensive emergency obstetric care, are often faced with budget shortfalls and human resource problems. With the end of the Manman Ak Timoun An Sante program, women in Port au Prince may face extra barriers to receive emergency obstetric care. As Thaddeus and Maine wrote when they developed the Three Delays model, the experience and risks for delay are contextual. Understanding the specific risks facing women in Port au Prince can help program planners at MSF, and within the Haitian MSPP, to develop programming to address these context-specific concerns.

Study Questions

This study aimed to identify behavioral, demographic, and clinical risk factors for first or second delays to access emergency obstetric care. This study addresses limitations in the available research on pregnant women's access to emergency obstetrical care in Port au Prince, Haiti. With no published literature reviewing the barriers to access for women with complications of pregnancy, this study helps to elucidate the specific contextual issues at play in this urban environment.

Research in other settings has found specific demographic, behavioral or clinical factors associated with increased risk of delayed access to emergency obstetrical care. No corresponding research exists for the urban Haitian context. What are the context-specific risk factors for delayed access to emergency obstetric health care in Port au Prince? Who are the women who have the most barriers to accessing care?

The types of delays to care in urban Haiti are not known. Are women experiencing long delays at home prior to deciding to access care? Is distance or transportation to the hospital a barrier to timely care? These first and second delays are contextually based, and the risk in this setting is not known. The types of delays experienced by women before receiving appropriate medical care for complications are unknown. Many studies reporting on first or second delays to accessing emergency obstetrical care fail to report on the length of delay.[138] The literature on the Three Delays has not developed a consensus on what time frame is clinically relevant for each of these delays. This study aims to measure and report on the time taken for each the first and second delay.

Pregnant women with preeclampsia represent an especially vulnerable group. There is no research in urban Haiti on the risks or barriers these women face to access emergency obstetric care. Additionally, data from other settings indicate that women with preeclampsia may have other demographic risk factors, including poverty and low educational levels. No research in Haiti has identified the specific characteristics of women with preeclampsia in this setting.

Finally, delayed access to health care has been shown to increase maternal and perinatal morbidity and mortality in many settings, including in rural Haiti. However, the link between delayed access to health care and poor maternal and infant outcomes in urban areas in general has few published reports[139–141], and none in Haiti. Is delayed access to emergency obstetrical care associated with poor maternal or neonatal outcomes? To answer these questions and address these critical limitations of evidence in the urban Haitian context, we conducted a study on delays to access emergency obstetric care for pregnant women admitted to the Centre de Références des Urgences Obstétricale (CRUO) hospital in Port au Prince.

Chapter 4: Methods

We conducted a mixed methods study on delays to access emergency obstetric care for preeclamptic and normal pregnant women admitted to the Centre de Références des Urgences Obstétricale (CRUO) hospital. Quantitative surveys were used to identify clinical, behavioral and demographic risk factors, as well as delays to access care. Qualitative in-depth interviews (IDIs) were employed to understand the meaning behind the identified factors. Interviews allowed researchers to probe individual experiences and perceptions of women.[142] Medical records review were used to collect maternal and neonatal outcomes.

In 2013, three percent of women at CRUO had an eclamptic seizure.[109] One in twenty infants delivered at CRUO were stillborn, and seven percent died before discharge from the hospital. Although many of these neonatal deaths can be attributed to prematurity caused by preeclampsia, it is unclear why some women experience poor maternal or neonatal outcomes, and why others with the same diagnoses do not. The CRUO hospital collects routine medical data for women admitted to the structure, but does not systematically collect demographic, clinical or behavioral data prior to admission that might shed light on women's risk factors prior to admission.

Study Objectives

Primary objective:

> To describe delays to care among preeclamptic women and women with normal pregnancy admitted to the Centre de Référence des Urgences Obstétricale (CRUO) in Port au Prince, Haiti.

Secondary objectives:

1. To identify demographic, clinical and behavioral predictors of delays to care for women diagnosed with preeclampsia versus those with normal pregnancy;

2. To analyze the relationship between delays in care for preeclamptic women and associated clinical consequences in the Haitian context;

3. To inform MSF's outreach and clinical care activities at CRUO in order to better target these activities to reach the highest risk pregnant women and to reduce their delays to receiving appropriate emergency obstetric care.

General study design

This study utilized a comparative cross-sectional design comprised of a quantitative survey, medical records review, and qualitative in-depth interviews to examine delays to care among women with preeclampsia versus those with normal pregnancy. Additionally, the study examined demographic, clinical and behavioral risk factors for delay to care, as well as the association between delay to care and poor maternal or neonatal clinical consequences.

A survey was administered to 502 women after delivery. After survey administration, medical records review was completed for each participant. Twenty-six of those selected women were recruited for qualitative in-depth interviews.

Women were interviewed after delivery, during the time of their postpartum stay at CRUO. The survey consisted of questions related to clinical, demographic, and behavioral risk factors, as well as questions related to delays to care. (Survey instrument Annex 9). Sample questions for each risk factor are found in Table 6. The survey was administered to the postpartum patient herself, or in cases of death or severe medical disability, to a legal representative who was able to give consent.

Additional information was collected from the medical chart, including maternal and infant outcome measures (Table 5).

Outcome measures

There are no guidelines in the Three Delays literature about the specific amount of time that qualifies as a first or second delay. In fact, even a very short amount of time could be categorized as a delay, as it lengthens the time between the onset of symptoms, and the administration of appropriate treatment. However, The United Nations Population Fund (UNFPA) gives a guideline of 6-12 hours for most complications of pregnancy (not postpartum). (http://www.unfpa.org/public/mothers/pid/4385) The World Health Organization states that most non-postpartum complications should be treated within 12 hours. (http://whqlibdoc.who.int/publications/2009/9789241547734_eng.pdf?ua=1) However, despite limited use of the six hour limit in the literature, there remains a lack of guidance in the published literature for what length of time qualifies as a delay.[143]

For this study, given the above limitations of the literature, and that we did not study postpartum complications, we used the more conservative, UNFPA-supported limit of six hours from the onset of symptoms to arrival at the MSF hospital. However, delay was recorded as a continuous variable, so that the association of delay to poor clinical outcomes could be investigated as a "dose-response" relationship, where longer delay would more likely lead to poorer outcomes.

This delay represents the total amount of time between the onset of complications or labor, and the administration of appropriate treatment at the hospital. If six hours or

greater has passed between the onset of complications and the patient's admission to MSF, that person would be characterized as having a delay. This delay could be due to either a delay in deciding to leave home (first delay), a delay in reaching the hospital (second delay), or a delay in receiving appropriate treatment (third delay).

The amount of time for the first and second delay were self-reported by participants in the survey. Participants were asked to report the amount of time elapsed between the onset of symptoms (or the precipitating event requiring health care) and when they left for the hospital- the first delay. They were also asked to report on the time to reach health care (whether MSF or another structure) - the second delay. The time each patient spent in the triage unit prior to being admitted was recorded from the medical chart - the third delay.

The onset of symptoms triggering the need for health care was different for each woman, and reflected individual and contextual factors, such as her level of education, previous experience with childbirth, and any relevant teaching about obstetric danger signs during antenatal care. The onset of these symptoms was necessarily subjective. The subjectivity in the understanding of biomedical pregnancy complications is an acknowledged component of the Three Delays model.[92]

Clinical results, including maternal and neonatal diagnoses (see Table 5) were transcribed from the patient's or infant's medical chart by study personnel after the participant gave consent. These secondary outcomes were recorded from the chart to reduce any reporting bias on the part of the participants, who may not be able to report medical terminology.

Clinical, demographic and behavioral risk factors were collected from the survey questionnaire (see Table 6). Clinical pregnancy history, such as history of medical or surgical problems in previous pregnancies, were self-reported by participants, because medical charts at CRUO do not always contain a complete medical or pregnancy history.

Table 4. Study Outcomes: Primary Outcomes

First Delay	How long did it take to decide to seek health care?
Second Delay	How long did it take to reach the hospital after deciding to seek care?

Table 5. Study Outcome: Secondary Outcomes, Poor Clinical Consequences

Maternal	• Eclamptic seizure • Coma • Death • ICU admission • Blood transfusion • Cesarean section
Neonatal	• Stillbirth • Neonatal death • Low APGAR score (<7 at 5 minutes) • NICU admission

Table 6. Risk Factors for Delays to Care, Examples of Demographic, Behavioral and Clinical Factors

Demographic	• Age • Neighborhood • Travel distance to CRUO (time) • Socioeconomic status • Employment • Marital status
Behavioral	• # visits to antenatal care • Use of traditional birth attendant • Visits to other health structures prior to MSF in labor (public hospital, private hospital) • Use of medications in pregnancy • Method, cost, and time of transport to MSF
Clinical	• Medical (history of hypertension) • Pregnancy history (previous cesarean section)

After approximately one month of quantitative data collection, qualitative interview participants were identified from women who had completed survey questionnaires. Potential interview participants were identified who had experienced long (>6 hour) delays to care. A random sample of interview participants was asked to participate in an hour-long interview to describe their experiences before and during admission to CRUO. Data was not collected that identified the number of women who declined to participate in an interview, or who were not available. In-depth interviews were scheduled during the second half of the data collection period. Both qualitative and quantitative data collection happened simultaneously during this time.

Study site

Study settings

The study took place in the postpartum department of the CRUO hospital in Port-au-Prince, Haiti. All surveys and interviews took place in private settings to ensure confidentiality. All survey interviews and in-depth interviews took place before the participants' discharge from CRUO. Survey administration and in-depth interviews occurred during free time at the hospital (i.e. not during medical rounds).

Participants- Case Definitions for the study population

We drew the study sample from two groups of women delivering at CRUO: women diagnosed with preeclampsia or eclampsia, and women diagnosed with a normal pregnancy in labor.

Case definition of Normal Pregnancy in Labor: A pregnant woman admitted to CRUO during study recruitment, with the diagnosis of "Physiologic Labor" or "Imminent Delivery" on admission.

Case definition of preeclampsia: A pregnant woman admitted to CRUO during study recruitment, with hypertension (blood pressure > 140/90) and significant proteinuria (> or = ++ on dipstick).

Case definition of eclampsia: A pregnant woman admitted to CRUO during study recruitment, with evidence of seizures, as well as a diagnosis of preeclampsia.

To ensure that women who died during labor or after delivery were not excluded from the analysis, which could bias study results, women were identified for inclusion at admission to CRUO. However, women were not approached for consent until after delivery. Women were not asked to consent for participation until their medical condition was stable and they were medically able to provide consent and participate.

For women under the age of eighteen, consent was also obtained from a parent or guardian. (see section - Minors) There was one survey administered to a family member in the case of a maternal death. All surveys were administered confidentially.

Participants- Inclusion and exclusion criteria

All women who delivered a baby at CRUO and had a medical diagnosis of preeclampsia or eclampsia, or physiologic pregnancy, were eligible for inclusion in the study. Qualified CRUO staffs that admitted the patient made the medical diagnosis and determined if the woman met the case definition.

Exclusion criteria for the study were women not diagnosed with either preeclampsia or eclampsia or normal labor, women who did not deliver an infant (i.e. women with preeclampsia who are discharged home before delivery), or women who did not speak Haitian Creole or French. Exclusion criteria also excluded women who were admitted to CRUO after delivery for postpartum problems, or those admitted to CRUO with gynecologic problems. Exclusion criteria included women who were conscious, but who were not mentally capable of understanding or giving informed consent.

Participants- Withdrawal

Consent to participate in the study could be withdrawn at any point and the patient did not suffer any negative implications for non-participation. Patients continued to receive the same standard of medical care from CRUO whether or not they decided to participate in the study. The consent process reviewed this information with prospective study participants. Study participants could also be withdrawn from participation by study personnel if they were unable to answer the majority of study questions. These

participants were excluded from data analysis, and excluded from the overall study sample.

Participant selection and enrollment

Identifying participants for the cohort

Study personnel created a list of names of women who met the study inclusion criteria from the triage register. This list was kept confidential, and was used only to identify women for potential inclusion. The list ensured that women who were admitted to CRUO, but who were not present in postpartum (cases of maternal death or Intensive Care Unit admission) were not missed. Study personnel used this list to identify women or their legal representatives in the postpartum ward, or the Intensive Care Unit. The list of potential study participants was cross-checked with the postpartum staff prior to approaching potential participants, who ensured that potential participants were medically able to participate in study activities. Participants were recruited after the end of morning medical rounds, to ensure that medical activities were not disrupted by study activities.

Consenting participants

Prior to consent, the Haitian research assistant informed each potential participant about the study rationale, objectives, duration, and possible implications for the participant. This information was given verbally and in writing in either French or Creole depending on the preference of the person. Implications included the benefits and risks of the study, which were clearly explained. Any question related to study involvement was answered. The subject understood that they had a choice regarding their participation in the study and that refusal to participate in the study would not affect their access to the standard of medical care given to all women in CRUO. The consent form was read

aloud, and, if agreed, signed. (See consent form Annexes 1-6).

After consent was obtained, the survey was immediately administered in a private location to ensure confidentiality. After the end of the survey, study personnel recorded selected medical data from the participant's medical chart on an attached form (see Annex 11).

For women with preeclampsia or eclampsia, the consent process was initiated as soon as the mother was well enough to give informed consent. For well-women the discussion began as soon as possible after birth as the mothers tended to stay in hospital only twenty-four to forty-eight hours.

Minors as study participants

Women who were less than eighteen years old were included for participation. There was no minimum age for participation. Adolescent mothers are at increased risk for complications of pregnancy, as well as being more at risk to develop preeclampsia and eclampsia, and it therefore was important to include their experiences in our analysis. However, to ensure protection of this vulnerable population, additional measures were needed, based on Haitian law. For the case of minor participants, surveys were still administered confidentially, even if consent was required from their parent or guardian.

In Haiti the mother is considered an adult at eighteen years of age. For mothers younger than eighteen years of age, the Bioethics Committee in Haiti gave the following guidelines:

o <18 years old living with and/or accompanied by parents (legal guardian)—The parents/legal guardians give consent.

o <18 years old NOT living with parents but living with a legal representative (family member, etc.)-- Legal representative can consent.

o <18 years old NOT living with parent and no legal representative- can be considered emancipated minor, and can give consent

If the minor participant had consent given by a legal guardian or legal representative, assent for study participation was still required of the participant herself. Study personnel read through the assent document with the minor participant and asked for their written assent (Annexes 7 and 8). The assent process occurred in a confidential space after legal guardian or representative had signed consent for participation.

For minor participants whose parent or guardian signed a consent form, assent, surveys and in-depth interviews took place between the patient and the study personnel in a confidential environment.

Consenting legal representatives of patients who are unconscious or dead

CRUO has a small number of maternal deaths or near-misses (i.e. patients admitted to the intensive care unit) every month. Information on their risk factors is crucial to understand barriers and delays to access care. Women who died prior to study admission, but who met other inclusion criteria, were included in the study through interviews with their legal guardians or legal representatives. Women who were unconscious and admitted to the Intensive Care Unit, but who meet other inclusion criteria, were also included in the study through interviews with their legal guardians or legal representatives. The Haitian Bioethics Committee gave the following guidelines:

- <18 years old and unconscious/dead: Same procedure as consenting a minor for participation, except no assent given by the patient
- >18 years old and unconscious/dead: If married, husband can give consent.
- >18 years old and unconscious/dead: If not married, then this would remain with next of kin (whether parents or family) but not friends.

The legal representative of the patient was asked to answer all survey questions to the best of their recollection, in place of the patient.

Ineligible and unrecruited participants

Women who did not meet inclusion criteria or who were ineligible for the study received the standard of care offered to all patients in CRUO. CRUO offers free medical care to women suffering a variety of obstetrical complications, which continued regardless of study inclusion.

Study and Clinical procedures

General

The study combined self-reported information from the participants, with information recorded from the medical chart. Surveys and interviews were arranged in a way to minimize the impact on time for the participants, and to minimize any interference with the medical care given to participants. Participation in the study did not alter the medical services offered to participants.

Training and pre-testing

Two research assistants were recruited. The research assistants were Haitian women with previous university attendance. It was not possible to recruit research assistants with previous research experience, given human resource constraints in Haiti. Haitian women were recruited, given that the vast majority of interviewees were also

women, leading to greater comfort for participants.

The recruited candidates underwent a weeklong training in research ethics, study protocols, and qualitative interview techniques (See Annex 13 for a detailed description). The qualitative research training occurred as a discursive, engaged conversation between the PI and two researchers. The group worked collaboratively through each section. Role-play between the PI and researcher was used to elaborate on concepts introduced in the curriculum. Both research assistants performed mock interviews with PI observation and supervision prior to the start of data collection.

Before the start of participant recruitment, the survey instrument, in-depth interview guide, and consent forms were piloted at CRUO, and necessary modifications were made. Modifications were submitted for IRB review, and approved.

Procedures for survey administration

Recruitment for survey participants occurred in the postpartum wards of the Emergency Obstetric Referral Hospital (CRUO) after the end of morning medical rounds. Study personnel had a list of women fitting the inclusion case definitions. Study personnel approached postpartum staff in CRUO to see if any woman on the list was not present (who may have died) or who was not medically cleared to be consented for participation. Women not able to independently walk, or be out of bed for an hour, or have any other medical risk factor as determined by CRUO staff were not medically eligible. Qualified CRUO staff decided who was medically eligible to participate. All participants had already delivered an infant at that time. Study personnel approached participants who were present and medically eligible at their bedside for study

recruitment. Study personnel identified themselves, and explained individually to each woman the purpose of the study and asked if they were interested to participate. If the woman responded affirmatively, study personnel asked the woman to either read, or be read, the informed consent form. The woman had at least fifteen minutes to read and consider the form.

Legal representatives of women who were admitted to the intensive care unit and who met other inclusion criteria were also approached for potential participation. If no legal representative was present, the woman was excluded from participation. Legal representatives were asked to participate on behalf of women who were cognitively impaired (i.e., unconscious). Women who were not unconscious, but who were not medically able to participate were approached for study participation when they were medically cleared, but still in the hospital.

Legal representatives of women who died at the hospital were also hoped to be included for study participation. However, almost all cases of maternal death that did occur during the data collection period either occurred to women who did not meet the inclusion criteria (i.e. did not have preeclampsia), or the family representatives were not available to interview (i.e. the woman died overnight). One survey was administered to a family member of a patient who died.

Study personnel verbally administered surveys in Haitian Creole or French, depending on the participant's preference. Responses were initially recorded on the paper survey. The primary investigator entered survey data into JMP (SAS Institute, Inc.) for analysis. Paper surveys are stored at the CRUO coordination office in a locked file for

five years after the end of study inclusions.

Procedures and data collection from medical chart

Patients admitted to the study already had a patient file from CRUO that included an in-depth account of their birth history and hospitalization. Data that was collected as part of the program that was used for the study included information about the woman's age; gravity and parity; her diagnoses of preeclampsia, eclampsia, multiple gestation, diabetes or obesity; whether or not she was admitted to the intensive care unit (ICU); whether she received a blood transfusion or a cesarean section; and whether or not she was in a coma. (See Annex 11 for complete instruments) Additionally, information about her infant was recorded from the chart, including neonatal intensive care unit (NICU) admission; estimated gestational age; weight; and heartbeat and APGAR at delivery. If the infant was admitted to the NICU, the admitting diagnosis was noted, though it was often missing from the chart.

The clinical data collection form was attached to the survey questionnaire. At the end of the survey, study personnel immediately filled out the medical data collection form using the patient's medical chart, which was located at the patient's bedside.

Procedures and data collection for in-depth interviews

Purposeful sampling was used to identify women for qualitative interview inclusion, from among participants who had completed the survey. While the planned sample size was thirty, interviews were suspended once data saturation was reached. Extreme case sampling[144] was used to recruit participants who had experienced delays to care, or poor maternal or neonatal outcomes, as identified through the survey and medical record review. These participants were ideally placed to report on barriers to accessing

care.

Women participating in the survey in months two and three of data collection, and who reported having delayed access to care or poor medical outcome, were consented for inclusion in the qualitative portion. Study personnel administering surveys prospectively identified interview participants with the identified factors. These women were approached for inclusion immediately following their survey participation. Interviews were then scheduled for a time later in the same day. Study personnel used an in-depth interview guide to question women (Annex 10). Interview guides included the same sequentially- assigned questionnaire number, to be able to link interview responses to risk factors identified in the survey. No personally identifiable information was recorded. Qualitative subjects participated in both the survey and the interview, for a total time commitment of one hour and thirty minutes, plus time for consent procedures.

Recruitment of qualitative participants started in the second month of study recruitment. At that time, both the qualitative and quantitative components ran simultaneously, with one research assistant focusing on each component.

The in-depth interview process was a guided conversation, which allowed the study participant to guide the direction of the conversation. As such, the interview guide prompted the interviewer to introduce themes to the participant. The participant's response guided the interviewer to ask follow up or probing questions to better understand the response. The interviewer sought to understand in detail the experiences of the research subjects, using non-verbal and verbal cues as well as non-judgmental listening techniques to encourage participants.

Haitian study personnel were trained before the start of qualitative data collection using a free curriculum developed by the Johns Hopkins Bloomberg School of Public Health (see Annex 13).[145] Interviews were conducted in Haitian Creole or French, depending on the participant's preference. Interviews were transcribed in the original language, and translated into English. Study personnel digitally recorded using commercially available digital technology. Back translation of selected transcripts ensured accuracy of translations. The researcher who conducted the in-depth interview used interview recordings to transcribe qualitative data in Haitian Creole into a Microsoft Word document. Each interview was then translated into English and then transcribed into another Microsoft Word document.

Potential confounders and effect modifiers

Some of the risk factors that we identified in this study may also function as confounders or effect modifiers of other risk factors. Our analysis plan took into account this possibility. However, based on the preeclampsia literature (see Chapter 3), we assumed that the following factors as potential influences:

- Age
- Multiple gestation
- Previous history of preeclampsia
- Diabetes
- Previous history of hypertension
- Obesity

Women admitted to CRUO for preeclampsia/eclampsia or normal pregnancies do not represent a random sample of all Haitian pregnant women, or even all Haitian pregnant women residing in Port au Prince. Only those women who are well-enough

informed to know of CRUO's presence, those with the ability to reach the hospital for admission, those with the specific admission criteria, and those well enough physically to make the journey were admitted. With an estimated forty percent of Port au Prince women delivering their infants at home, we cannot claim to draw conclusions for all pregnant Port au Prince women from our study. However, based on existing surveillance data,[109] CRUO does admit a large proportion of all women delivering in hospitals every month in Port au Prince.

Our study cannot draw conclusions for barriers faced by all pregnant women in Port au Prince, only those who are admitted to CRUO. Further research would be needed to identify and analyze barriers to access for those women who deliver in other health structures, or at home.

Statistical Considerations

Sample size for the quantitative survey

This study included a group of women with no known complications of pregnancy, and a group of women with their current pregnancies complicated by preeclampsia or eclampsia. The study aimed to identify delays to care and poor clinical consequences in the group of women diagnosed with preeclampsia or eclampsia and compare them to a group of women with no known complications, "normal" women.

The sample size for this descriptive study was calculated using delay to care as the outcome. The population-based DHS, conducted in 2012, showed that almost seventy-five percent of urban pregnant women in Haiti experienced a difficulty accessing health care during their most recent pregnancy.[3] Although the DHS does not specify whether these difficulties led to delay in accessing health care, it is a reasonable

assumption. We can expect that women with complications of pregnancy at CRUO may have a similar likelihood of delay to care, regardless of whether or not they were diagnosed with preeclampsia.

It was expected that clinical, demographic or behavioral risk factors, or exposures, contributed to these delays. The prevalence of these risk factors is unknown. Distance to the nearest health center was found in one study in rural Haiti to be the largest factor in access to prenatal care. We assumed that distance to the hospital could have been the most important factor in delay to emergency obstetric care. Even in the urban setting of Port au Prince, the logistics and cost constraints of transport remain an issue. This question has never been addressed in this context for emergency obstetric care. We assumed that twenty percent of women live more than an hour away from the hospital, a conservative estimate given the logistical challenges of travel in Port au Prince. This prevalence would likely be similar between women diagnosed with preeclampsia, and those with low-risk pregnancies. Women not exposed to this risk factor (of living far away) could be assumed to have a lower risk of delay, estimated at a 50% risk of delay.

The exposed group, the women who live far away, were measured in the amount of time taken for them to reach the hospital, by whichever method they chose to come. Women who took one hour or longer to reach the hospital (whether by walking, public transit, or other means), were categorized as "exposed". Therefore, the "unexposed" group comprised women whose travel time to the hospital in this instance was less than one hour.

Given the logistical challenges of travel in Port au Prince, it was determined that

time was the best indicator of distance to the hospital, rather than kilometers. Different neighborhoods that may be equidistant to the hospital have different access to public transportation, and traffic patterns in this congested city can lead to long travel times even for short distances.

The sample size was calculated to show differences in delayed access to care between the women exposed to a behavioral, demographic or clinical risk factor, and those who did not have a risk factor. We used the following assumptions then for the calculation of the sample size: 1) two-sided significance level of 95%; 2) power of the study 80%; 3) ratio of unexposed/exposed (4:1); 4) expected relative risk of delayed access in the exposed group 1.5; 5) expected proportion of outcome in unexposed group 50%. This generates a sample size calculation of 42 women in the exposed group (women who live far away) and 168 women in the unexposed group (women living close to the hospital), a total of 210 women.

Three months were available for data collection, given CRUO and primary investigator constraints. Two research assistants worked during that time. Both research assistants recruited, consented and administered survey questionnaires during the first month of data collection. During the second and third month of data collection, one research assistant continued full time with survey administration, while one research assistant focused on qualitative interviews. With these constraints, surveys and in-depth interviews were completed in the three-month data collection time-frame.

Analytic methods - Quantitative data analysis

We first calculated the proportion of women who experienced either first or second delay in accessing obstetric care. We then calculated the proportion that experienced a long total delay (first, second and third delay). Proportions were stratified by medical diagnosis, preeclampsia or no preeclampsia. The relative risk of experiencing long delay was calculated for the preeclamptic and normal groups.

We then examined the association between delays and poor clinical outcomes. A bivariate analysis was conducted to calculate the association between the exposure of delayed access to health care to the outcome of a poor clinical result. Findings were presented as relative risks with 95% CI.

The analysis also examined the relationship between clinical, demographic and behavioral risk factors and delay. We calculated the association between the exposures of each individual antecedent risk factor (whether behavioral, demographic or clinical) to the outcome of delayed access to health care.

Analytic methods - Qualitative data analysis

Transcripts of in-depth interviews were entered into NVivo, a qualitative data analysis software program, for data analysis (QSR International). Analysis of qualitative data occurred in an iterative fashion, as data was collected, allowing researchers to formulate new lines of inquiry.[142] Interview data analysis included coding the transcripts for themes, using principles of grounded theory. Words or phrases describing an idea or phenomena were given a code, which was then compared and examined. Codes were data-driven, meaning they developed from the themes emerging from the data. In-depth analysis of coded data developed conceptual models to understand barriers to access for

pregnant women. Qualitative data was linked to the respondent's survey responses by a sequentially numbered "questionnaire number", which was recorded on the interview transcript.

Quality control

Assuring the quality of our data collection and compilation was a top priority. This was managed at field level by the principal investigator.

Quality control measures for the quantitative data collection included spot checks of hospital data by the primary investigator and ongoing training and coaching of research assistants. Study personnel double checked clinical data from surveys against hospital medical data in the chart (for instance, number of children delivered) to ensure accuracy.

Quality control measures for qualitative data collection included the use of recording devices to ensure accurate transcription of interviews. Interviews were transcribed in the original language before translation to English. All quantitative and qualitative data was stored in password-protected files, and only accessed by the PI.

Ethical Considerations

Benefit for participants and community

There were no direct benefits to participants.

Confidentiality

Any and all data collected throughout the study remained strictly confidential. The digital recordings, which did not include any identifying information, were saved to an external hard drive, which is locked with the paper consents and surveys at CRUO. This external hard drive will be deleted after five years.

The paper forms- surveys and consent forms- are being kept in a locked box for five years beyond the end of the study. At the end of this time, the paper forms will be burned in the biomedical incinerator on site at CRUO.

The patient's identities were not recorded on any study documentation. The patients' age and diagnosis were recorded, but not the date of delivery. Given the large number of patients with the same diagnosis, it would be impossible to deduce the identity of any patient from this information. All documentation and files contained only the patient's file number, which was not linked in any way to personally identifiable information.

Recordings of in-depth interviews were also kept locked. Recordings did not include personally identifying information, including name or address.

Participants were assured that there is no way that information in the study files could lead to identification of the participant. This statement was also included in the consent form and was verbally discussed when consent was signed. Data was entered into databases that are password protected and did not include personally identifiable information. All paper versions of patient forms, and recordings of interview data, will be kept in secure medical data storage facilities for five years following the completion of the research. After five years, the information will be destroyed in CRUO's biomedical incinerator.

Cooperation with national and local partners

The study of preeclampsia and hypertension in Haiti is a national priority.[146] Dr. Roger Jean-Charles, professor of internal medicine at the State University of Haiti, and

past president of the Haitian Hypertension Center, is a consultant for this study. Dr. Jean-Charles will assist with the dissemination of research findings within the MSPP and among Haitian health care providers. During the study implementation phase, meetings were planned with Dr. Jean-Charles to discuss the research.

The study was also discussed with the department of maternal and child health at the MSPP. The MSPP supports the implementation of the study, although they did not take an active role. All results of the study will be shared with this department.

Benefits for the program, community and nationally

Preeclampsia is estimated by one Haitian study to affect almost one in five Haitian pregnant women. Understanding the risk factors for poor outcomes in the Haitian context is crucial to developing effective programming to prevent infant and maternal mortality. With no current research available on these risk factors, this study will help lay the groundwork for further research, and for more effective public health programming.

MSF, as a leading provider of emergency obstetric care in Port au Prince, was ideally positioned to host this research study. As urban migration towards the capital city of Port au Prince continues, the issue of effectively targeted emergency maternity services will only continue to increase in importance. As an emergency obstetric service, CRUO needs information on its patients and their risk factors in order to efficiently and effectively offer services. This study offers important insights into the groups of women most at risk.

Current outreach and surveillance activities at CRUO focus on the programs and

capacities of other maternal health actors, but have limited abilities to assess medical needs of potential patients. The surveillance teams that are implementing these activities at present have limited understanding of the reasons that make women admitted to CRUO vulnerable to high levels of morbidity. Analysis of data collected in this study will inform MSF strategic planning to target women most at risk for poor pregnancy outcomes, and to improve access to timely emergency obstetric care. Haiti is one among many countries in the world facing a growing urban population. Identification of factors associated with delays to care among urban women in Haiti may also inform programs in other urban areas where MSF works.

Understanding the humanitarian context and experiences of CRUO patients helps deepen the understanding of risks and barriers to access. This information can be used to develop prospective data tools to collect and analyze data on future CRUO patients.

Incentives and compensation

No financial incentives were offered to participants. All study activities took place during the period of the patients' hospitalization. Therefore, participants did not incur travel costs or loss of time other than that already spent in the hospital.

Potential risks

We see very few potential risks of this study. This was a survey and interview to examine the risk factors for women who received medical care in the facility. All women were offered the same level of care based on their medical needs. The minimal risk to study participants included the risk of a breach of confidentiality and the time lost completing the survey or in-depth interview. Women were not directly questioned about sensitive topics, such as experiences of violence, though they could have chosen to

divulge them during in-depth interviews. Any woman divulging experiences of violence or other sensitive topic was offered a referral to the mental health department available to all women at CRUO.

We interviewed some women who experienced poor outcomes for themselves or their infant. The fact of questioning these women after a poor outcome, especially the death of an infant, was potentially very upsetting. The informed consent procedure emphasized the voluntary nature of participation, and the ability to withdraw from the study at any time. For any woman who appeared upset during the survey or interview, study personnel offered to stop. Any woman who requested to stop participation, or who was upset during or after participation had access to CRUO's mental health services.

To minimize the risk of a breach in confidentiality, several measures were in place. Neither the survey nor the interview asked participants any personally identifying information. The recorded interviews did not record the subjects' names or other identifying information. Medical data from the chart was collected at the end of the survey, so that names or other identifiers were not needed to locate this information at a later time. All surveys and interviews took place in a private, confidential environment to ensure confidentiality. Consent forms, which did include patient names, were stored in a locked file, but were not linked in any way to survey or interview responses.

To minimize the risk of time lost, all study activities took place during a woman's postpartum hospitalization. The study minimized the risk of disrupting medical activities by coordinating participant recruitment and interviews with CRUO medical personnel. Consent, questionnaires and interviews took place after the end of daily medical rounds

in the postpartum ward. Additionally, study personnel asked for medical clearance from the postpartum supervisor to approach women for potential study inclusion.

This study took place at the same time, and in the same location, as another research study investigating long-term outcomes of low-birth weight infants. Both studies recruited participants simultaneously, so measures were put in place to ensure both random selection of participants, but not recruiting participants into more than one study (for instance, alternating weeks of inclusion for each study). Both the medical director of the hospital and the medical coordinator of the mission were involved to ensure that both studies did not impose greater risks on hospital operations or on potential study subjects.

CHAPTER 5: QUANTITATIVE RESULTS

Overview

This mixed methods study, involving a quantitative survey and interviews with post-partum Haitian women, identified delays to care for preeclamptic and normal women, as well as numerous obstacles women overcame to reach care. Qualitative data enriched quantitative findings by allowing women to describe in detail their experiences in their own words.

To ground the presentation of findings, we present the study objectives again here. The primary study objective was to describe delays to care among preeclamptic women and women with normal pregnancy admitted to the Centre de Référence des Urgences Obstétricale (CRUO) in Port au Prince, Haiti. Secondary objectives included identifying demographic, clinical and behavioral predictors of delays to care for women diagnosed with preeclampsia versus those with normal pregnancy; and analyzing the relationship between delays in care for preeclamptic women and associated clinical consequences in the Haitian context. Finally this study aimed to inform MSF's outreach and clinical care activities at CRUO in order to better target these activities to reach the highest risk pregnant women and to reduce their delays to receiving appropriate emergency obstetric care.

A total of 502 surveys were administered to women admitted to the Médecins Sans Frontières (MSF) obstetric emergency hospital in Port au Prince. Surveys aimed to identify and quantify delays to access care, as well as the risk factors for those delays. Surveys asked women a series of questions regarding their demographic, clinical and

behavioral risk factors. The results were then stratified by preeclampsia status. Analyses included univariate and bivariate statistical modeling.

The initial sample size for the quantitative survey was 420 women. After one month of survey data collection, about 30% of preeclamptic women were not able to report on either the first or second delay, based on preliminary data analysis. Those women were sick at the time they came to the hospital, and some of them may have also been unconscious (i.e. women who had an eclamptic seizure). After approval from relevant IRB, more preeclamptic women were recruited, in order to ensure adequate statistical power. The sample size of 210 women was augmented by an additional 82 women, a total of 292 preeclamptic participants, to account for a 30% non-response rate. This assumes a similar rate of non-response to the first or second delays among the additional participants.

Twenty-two women were withdrawn from the study who could not complete the study questionnaire. All of these women had suffered eclamptic seizures and were unable to remember enough information about the events prior to their hospitalization to answer survey questions. These women were withdrawn from participation by study personnel after their participation in the study started, and it became clear that they were unable to answer the majority of survey questions. Some other participants were unable to answer the length of first or second delay but responded to most other questions; they were not withdrawn.

Qualitative interview participants were chosen from among the survey participants. A random sample of participants who had experienced a long delay (> 6

hours) were asked to participate. A total of twenty-six interviews were conducted, eighteen with women, and eight with caregivers, which were recorded, transcribed, translated, and analyzed as previously described. The total sample size depended on theoretical saturation, the point at which no new themes emerged. We estimated, based on other qualitative research, that the total sample size would be about thirty women. Finally, twenty-six qualitative interviews were conducted.

Quantitative Results

Background characteristics of survey respondents

Demographic characteristics of the entire sample are presented in Table 7. The majority of women who participated in this study were married, Christian, had finished at least primary school education, and were unemployed. The vast minority of the study participants self-reported "doing well" or "good" socioeconomic status (7.3%). About a quarter (22.9%) of study participants were living with family members or friends at the time of the survey (data not shown).

Preeclamptic women in this study were on average older than normal women (29.7 years versus 27.2, $p< 0.01$), despite similar proportions of multiparous women in each group (data not shown). Eight percent of the women in the preeclampsia sample were age forty or older, versus only 2.4% in the normal sample ($p<0.01$). Age greater than forty is a risk factor for preeclampsia.

A greater proportion of preeclamptic participants reported having a religious affiliation (95.2 % versus 88.0% , $p <0.01$), owning their own home (47.3% versus

30.5%, p<0.01) and being internally displaced (2.8% versus 0.5%, p = 0.04), compared to normal women. Of the women with a religious affiliation, all but one identified as Christian.

Some demographic indicators were similar between the preeclamptic and normal groups. Preeclamptic and normal women were similar in terms of marital status, educational completion, and formal employment. In both groups, only a very small proportion of women reported “doing well” or "good" economic status (5.8% normal and 8.7% preeclamptic participants, n.s.).

Table 7. Demographic characteristics of study participants, by preeclampsia status

	Normal n (%)	Preeclamptic n (%)	*p*-value
	n = 210	*n = 292*	
Mean age (SD)	27.2 (6.2)	29.7 (6.8)	**<0.01**
Married or cohabitating	149 (71.3)	223 (76.4)	0.20
Attended some secondary school or university	152 (73.1)	206 (71.3)	0.66
Employed in formal sector	15 (7.4)	16 (5.6)	0.43
Had religious affiliation	184 (88.0)	276 (95.2)	**<0.01**
Own home	64 (30.5)	138 (47.3)	**<0.01**
Internally displaced	1 (0.5)	8 (2.8)	**0.04**
“Doing well” or “good” (reported economic status)[1]	12 (5.8)	25 (8.7)	0.22

[1] Economic status self-reported via four-item scale using locally appropriate terminology, choices

A large proportion of preeclamptic participants were not able to report delays to care. Neither these women nor their relatives could complete the majority of the study questions (because they had been unconscious as the result of an eclamptic seizure during part of the first or second delays) and so were withdrawn by researchers from the study. Demographic characteristics of these women were compared to women in the preeclampsia subgroup (Table 8). There were smaller proportions of women who were married, who had a religious affiliation, or who reported "doing well" or "good" in terms of economic status among the preeclamptic women who could not report first delays, and the women who withdrew.

Table 8. Demographic characteristics of study participants who could not report first delay (including women who withdrew), compared to other preeclamptic women

	Preeclamptic women who did not report first delay, or who withdrew n (%)	All Preeclamptic n (%)	*p*-value
	n=29	*n=285*	
Mean age (SD)	28.1 (7.3)	29.6 (6.6)	0.28
Married or cohabitating	17 (58.6)	220 (77.2)	**0.04**
Attended some secondary school or university	17 (58.6)	201 (71.3)	0.17
Employed in formal sector	0 (0)	16 (5.7)	0.08
Had religious affiliation	23 (79.3)	269 (95.1)	**<0.01**
Own home	16 (55.2)	133 (46.7)	0.68
Internally displaced	0 (0)	9 (3.2)	0.18
"Doing well" or "good" (reported economic status)[b]	0 (0)	25 (8.9)	**0.03**

[b] Economic status self-reported via four item scale using locally appropriate terminology, choices included "doing well", "good", "not too bad" and "no money"

Health history

As seen in Table 9, a slightly higher proportion of preeclamptic women in this study were giving birth for the first time (nulliparous) compared to normal women, though the difference was not statistically significant (48.1 % to 43.0% for normal, p=0.27). Among multiparous women, preeclamptic participants were also much more likely to have a history of a birth complication than the normal participants (21.6% versus 2.7%, p<0.01). A slightly greater proportion of preeclamptic participants had a history of health problems or previous doctor visits, although this difference did not meet the level of statistical significance.

The women in the preeclamptic subgroup were also much more likely to have had a diagnosis of preeclampsia in a previous pregnancy (38.6% versus 8.8%, p<0.01). However, almost ten percent of normal women in this study also reported a previous history of preeclampsia, roughly double the expected proportion of preeclampsia found among pregnant women in most settings, according to published estimates.[49]

Table 9. Health history prior to current pregnancy, by preeclampsia status.

	Normal, n (%)	Preeclamptic, n (%)	*p*-value
Entire Sample n= 502[c]	*n=208*	*n= 292*	
Previous doctor visit	48 (23.1)	85 (29.1)	0.13
Previous health problem	48 (23.1)	83 (28.5)	0.17
No prior delivery (nulliparous)	86 (43.0)	139 (48.1)	0.27
Among multiparous mothers only n=253	*n=113*	*n = 140*	
Prior preeclampsia	10 (8.8)	54 (38.6)	**<0.01**
Birth complication in prior pregnancy[d]	3 (2.7)	30 (21.6)	**<0.01**
Prior home birth	33 (29.5)	39 (27.9)	0.78

[c] Due to non-response to some questions, sample does not include all survey respondents
[d] Birth complications were self-identified by participants and included a history of cesarean section, fetal death, and eclampsia

Despite having higher rates of complications and preeclampsia in previous pregnancies, preeclamptic women in this study had comparable rates of prior out-of-hospital birth.

Behavioral risk factors

Participants were surveyed about their health behaviors during the current pregnancy, including antenatal care usage, visits to traditional birth attendants, and medication usage. Table 10 presents behavioral risks by preeclampsia status, compared to relevant DHS data, and indicates that preeclamptic and normal women in this study reported comparably high rates of antenatal care (ANC) usage (96.7% normal, 96.2 % preeclamptic group), mirroring trends among women in Port au Prince overall (91.9%, DHS data).[3] Adequate ANC, defined by the WHO as four or more visits, was achieved by a slightly lower proportion of women, similar between both the preeclamptic (83.1 %) and normal (84.2%) women. This is higher than expected based on DHS survey data of women in Port au Prince, which found that 74.6% of women had four or more ANC visits.[3] Similar proportions of both women who delivered preterm (<37 weeks gestation), and women who delivered very preterm (<32 weeks gestation) reported receiving four visits of ANC as women who delivered at term (84%, data not shown).

Almost half (46.9%) of preeclamptic women in this study had received a diagnosis of preeclampsia prior to their admission to CRUO. Despite this, less than one third (31.9%) of preeclamptic women were able to recall any danger sign of worsening preeclampsia, such as headache or facial swelling, although some of the preeclampsia diagnoses may have been made by the referral facility at the time of the labor and birth.

In comparison, only 7.2% of women in the normal group reported having received a diagnosis of preeclampsia during the current pregnancy.

Table 10. Behavioral risk or protective factors of study participants, by preeclampsia status, compared to relevant DHS data

Factor	Normal: n (%)	Preeclamptic: n (%)	*p*-value	Women in Port au Prince[3] (DHS, 2012, %)
	n = 210	*n = 292*		*n= 1 037*
ANC[e] with health professional	203 (96.7)	281 (96.2)	0.80	91.9
Adequate ANC (4+ visits)	171 (84.2)	231 (83.1)	0.74	74.9
Diagnosis of preeclampsia in current pregnancy	15 (7.2)	136 (46.9)	**<0.01**	
Birth plan made with health professional[f]	191 (91.0)	258 (89.0)	0.35	
Birth plan made with TBA	35 (77.8)	38 (66.7)	0.18	
ANC with TBA	43 (20.6)	61 (20.9)	0.77	0.4% (ANC with untrained health staff)
Remembered any preeclampsia danger signs	31 (14.8)	93 (31.9)	**<0.01**	
Any medications taken in pregnancy	193 (91.9)	266 (91.1)	0.34	
Medications prescribed by health professional	191 (91.0)	267 (91.8)	0.20	
Antihypertensive medications reported	0 (0)	38 (13.0)	**<0.01**	
Did not remember the name of medications taken	86 (41.0)	102 (34.9)	0.17	

[e] ANC = Antenatal care. DHS= Demographic and Health Surveys. TBA= Traditional birth attendant.

[f] Birth plans refer to a discussion between provider and patient about her intentions and plans for her birth.

Almost all women in this study (91.0% normal, 91.8% preeclamptic group) reported taking medication that was prescribed by a doctor or nurse during the pregnancy. Most participants reported taking prenatal vitamins (data not shown). Thirty-seven women (13.0% of preeclamptic women), all from the preeclampsia group, also reported taking anti-hypertensive medications, such as methyldopa (identified as "AMD" by study participants). Five women in the preeclamptic group (1.6%) reported taking aspirin, which is recommended for women at high risk of preeclampsia to prevent maternal and neonatal morbidity and mortality.[147] No participant reported taking calcium, which is another recommended prevention measure.[148] About two hundred women (38.2%) were unable to name or had forgotten the name of the medication they took (data not shown).

Traditional birth attendants (TBA, or "matrone") were also used by many women in this study. About a quarter of women reported seeing a TBA for antenatal care during this pregnancy. Of these women who saw a TBA for antenatal care, the vast majority (96.4%) also saw a doctor or nurse for antenatal care. The proportion of women seeing a TBA was similar between the normal (20.6%) and preeclamptic (20.9 %) groups. Most women who had seen a TBA for antenatal care reported that the TBA discussed their plan for where and how they would give birth, more for the normal (77.8%) than the preeclamptic (66.7%) group, though the difference was not statistically significant ($p=0.18$). The percentage of women reporting antenatal care with a TBA in our study was more than fifty times greater than that found by the DHS in 2012. Prenatal care services by untrained health staff, which corresponds to both "traditional birth attendants", as well as "relative or friend" in the DHS survey questionnaire, was reported

as 0.4% of women in the Port au Prince area.[3] It is unclear why the reported percentage of women using TBA in this study is so much greater than women surveyed by DHS.

Primary Outcome - Delay to Accessing Obstetric Care

First Delay (deciding to leave home to seek care)

Table 11 presents the summary of data concerning the Three Delays.[67] The first delay is defined as the time period between the start of the obstetric emergency, and the decision to leave home.[67] The survey instrument first asked women to identify the sign or symptom that indicated there was an emergency, and then asked them to identify the amount of time that passed before they decided to leave for the hospital. For some women, primarily those who had experienced a normal delivery and not diagnosed with preeclampsia, the sign was the onset of labor. For preeclamptic women, and those not at term (less than nine completed months of pregnancy as determined from the medical record), the reported signs included headache, edema and convulsions.

The women in this study reported a mean 11.5 hours first delay (SD 22.2 hours). Preeclamptic women had a significantly longer mean delay than normal women (13.5 hours (SD 30.0) versus 5.5 hours (SD 10.5), ($p< 0.01$). The median delay for both groups was much shorter, however and similar for the two groups, (2 hours, interquartile range (IQR) = 12 for preeclamptic women versus 3 hours, IQR=5 for normal women).

Second Delay (the time from the decision to leave to the arrival at the hospital)

The second delay was defined as the time it took women to arrive to the hospital once they had decided to leave home. Women in this study experienced a mean second

delay of about an hour. The mean second delay was similar for preeclamptic women (1.2 hours) than normal women (1.0 hours, p=0.20).

Table 11. First, Second, Third, and Total Delay in Preeclamptic and Normal groups

	Normal Women	Preeclamptic Women	*p*-value
First Delay (hours)	*n = 207*	*n = 285*[g]	
Mean (SD)	5.5 (10.5)	13.4 (30.0)	**<0.01**
Median (interquartile range)	3.0 (5.0)	2.0 (12.0)	
Second Delay (hours)	*n = 194*	*n = 251*	
Mean (SD)	1.0 (0.6)	1.2 (1.0)	0.20
Median (interquartile range)	1.0 (0)	1.0 (0)	
Third Delay (minutes)	*n = 208*	*n= 292*	
Mean (SD)	11.6 (38.1)	49.7 (60.2)	**<0.01**
Median (interquartile range)	0 (0)	35.0 (70.0)	
Total Delay (hours)	*n= 191*	*n= 235*	
Mean (SD)	6.8 (10.5)	14.6 (27.9)	**<0.01**
Median (interquartile range)	4 (5.0)	5 (10.6)	

[g] Some participants were unable to recall the length of delays, so not all survey respondents are included in the analysis of each delay.

Third Delay (length of time spent in triage before being admitted to hospital)

The third delay was defined as the time the woman spent in triage prior to admission. The length of third delay was significantly longer for preeclamptic women (49.7 minutes) than normal women (11.6 minutes) (p< 0.01). Normal women admitted to CRUO were typically admitted because they were very close to delivery. A sub-analysis of preeclamptic patients found that the sickest women in this group, who had eclampsia, had a significantly shorter third delay than preeclamptic women overall (17.5 minutes versus 53.6 minutes, p<0.01, data not shown).

Total Delay (Sum of First, Second and Third Delays)

Preeclamptic women in this study experienced a longer total delay in accessing emergency obstetrical care than the normal women (mean 14.6 hours versus 6.8 hours, $p<0.01$). The median total delay was five hours for preeclamptic women, and four hours for normal women ($p < 0.01$). Longer delays among the preeclamptic group were attributable primarily to longer first delays. Waiting longer to leave home led to longer delays to emergency care for preeclamptic participants than the normal participants in this study. When evaluated as a dichotomous variable (long delay >6hrs, not long delay), preeclamptic women also were more likely to experience long delay (43.8% preeclamptic women versus 33.5% normal women, p=0.03, RR 1.3, 1.0-1.7 95% CI, data not shown).

Mean delays for the preeclamptic group were longer than median delays due to the skewed distribution of the data. Twenty-four preeclamptic participants had delays longer than 48 hours, and for thirteen of those women, their delay was longer than 72 hours (see Annex 14). An analysis of this subgroup of women with extremely long delays (greater than seventy-two hours) shows that they had generally developed preeclampsia at an earlier gestational age. A greater proportion of these women were admitted preterm (84.6% versus 38.6%, $p<0.01$), and had a low birth weight baby (83.3% versus 46.3%, $p<0.01$) than women in the preeclampsia subgroup overall. Analysis of the relationship between delays greater than twenty-four hours, or forty-eight hours did not show any statistically significant differences among these outcomes.

In addition to the women with extremely long delays to care, many more of the preeclamptic participants experienced long delays. Almost half of these study

participants had a clinically relevant (>6 hour) delay to accessing emergency obstetrical care when faced with a life-threatening complication. Almost one-fifth (17.0%) of the preeclamptic women had a delay of at least twenty-four hours before receiving care. The difference in total delay between the preeclamptic and normal groups is primarily the result of a longer first delay in the preeclamptic group. However, the third delay was also longer in the preeclamptic group than in the normal group.

Demographic indicators were also evaluated for the group of preeclamptic women who experienced very long delay (>24 hours). No demographic differences were found, with the exception of economic status. There was a smaller proportion (0%) of women in the very long delay group who reported "doing well" or "good" economic status than compared to the preeclampsia group overall (9.5%, $p<0.01$). All other demographic indicators, including occupation, housing, and education were similar between the groups (data not shown).

Secondary Outcomes

In addition to identifying and quantifying delays to care, the study also assessed the risks factors for delayed access to care, as well as the impact of these delays on the clinical outcomes of mothers and babies.

Maternal outcomes

Large proportions of women and infants experienced poor clinical outcomes. For women, preeclampsia was associated with greater likelihood of cesarean section (RR = 10.5, 6.2 - 18.0 95% CI) , intensive care unit admission, coma, eclampsia, and transfusion, compared to non-pre-eclamptic women, although the numbers of poor

outcomes for the normal group were very small (Table 12). Almost one in nine (10.7%) of preeclamptic women in this study also experienced an eclamptic seizure, not including the twenty-two women who were withdrawn, who all had eclampsia.

Table 12. Distribution of poor maternal outcomes for normal and preeclamptic women

	Normal Group n (%)	Preeclamptic Group n (%)	Relative risk of preeclampsia exposure (95% CI)	*p*-value
	n = 210	*n = 292*		
ICU[h] admission	1 (0.5)	31 (10.7)	22.4 (3.1-162.6)	**<0.01**
Coma	0 (0)	5 (1.7)	-	**0.02**
Transfusion	1 (0.5)	10 (3.5)	7.3 (0.9-56.4)	**0.01**
Eclampsia	0 (0)	31 (10.7)	-	**<0.01**
Cesarean section	13 (6.2)	190 (65.3)	10.5 (6.2-18.0)	**<0.01**

[h] ICU= Intensive Care Unit

Neonatal outcomes

For newborns, a preeclampsia diagnosis for their mothers was associated with greater likelihood of neonatal care unit (NICU) admission, stillbirth, low birth weight (<2.5 kg), and APGAR score less than 7 at 5 minutes of life (Table 13).

Table 13. Distribution of poor neonatal outcomes among normal and preeclamptic groups

	Normal Group n (%)	Preeclamptic Group n (%)	Relative risk of preeclampsia exposure (95% CI)	*p*-value
	n = 210	*n=292*		
NICU admission[i]	32 (15.4)	131 (45.6)	3.0 (2.1-4.2)	**<0.01**
Stillbirth	1 (0.5)	29 (9.9)	20.9 (2.9-151.9)	**<0.01**
Low birth weight	31 (15.0)	144 (50.0)	3.3 (2.4-4.7)	**<0.01**
APGAR <7 at 5 min[j]	21 (10.1)	67 (25.6)	2.5 (1.6-4.0)	**<0.01**

[i] NICU= Neonatal Intensive Care Unit
[j] Excluding stillbirths

Risks for delay

None of the demographic, clinical or behavioral risk factors had significant associations with total delay (Table 14). Although there were longer delays for women with some of these risk factors, the small numbers in many of the categories limited statistical power. The lack of statistical significance for most factors was true regardless of whether delay was measured as a binary or continuous outcome.

Table 14. Length of total delay (in hours) by preeclampsia status and demographic risk factor.

	Normal Group			Preeclamptic Group		
	Yes: length of delay (n)[k]	No: length of delay (n)	*p*-value	Yes: length of delay (n)	No: length of delay (n)	*p*-value
Partnered	6.3 (134)	7.1 (56)	0.66	14.0 (180)	16.5 (53)	0.57
Secondary/ University Education	6.7 (139)	7.2 (50)	0.74	14.3 (169)	15.9 (62)	0.69
Formally employed	6.9 (15)	6.9 (170)	0.99	18.5 (14)	14.3 (214)	0.59
"Doing well" or "good" economic status	12.1 (9)	6.6 (179)	0.13	4.9 (18)	15.2 (211)	0.13
Owns home	6.2 (58)	7.4 (122)	0.39	16.2 (110)	13 (114)	0.69
Internally displaced	4.0 (1)	6.9 (187)	0.79	13.1 (6)	14.8 (223)	0.88

[k] Survey participants were excluded who did not answer length of delay

There was a slight trend towards shorter delay among preeclamptic women with good economic status (4.9 hours versus 15.2 hours for those with poor economic status), although this did not reach statistical significance and the median differences were much more similar (3.9 hours normal women versus 5 hours for preeclamptic women). This trend was opposite among the normal group, with longer delays among the women with good economic status (mean 12.1 hours versus 6.6 hours), although again, not statistically

significant.

Among preeclamptic women with very long total delays (>24 hours, n= 40), demographic factors were similar to the rest of the preeclampsia group. Women with a very long delay were even less likely than the other preeclamptic women to report "doing well" or "good" economic status (0% versus 9.4%, p<0.01), and were more likely to report a religious affiliation (100% versus 81.9%, p=0.03). Other demographic factors were not statistically different between the two groups (data not shown).

Participants' neighborhood of residence was also evaluated as a risk factor for delay. Neighborhoods were categorized by zone within Port au Prince (see Annex 12). Delays by neighborhood were compared between preeclamptic and normal participants (see Table 15). Women from different neighborhoods did not experience statistically different delays, but there were trends towards longer delays from some neighborhoods among the preeclamptic participants. Long total delays in this sample were mostly due to first delay (delay in leaving home) and not second delay (travel time).

Table 15. Length of delay (hours, [SD]) in preeclamptic and normal groups by neighborhood of residence

	Normal Group		Preeclamptic Group		p value
East (Delmas)	6.8 (11.5)	n= 73	14.3 (28.2)	n=69	**0.04**
North (Bon Repos)	6.7 (12.4)	n= 36	9.1 (15.8)	n=37	0.48
Downtown Port au Prince	5.1 (4.6)	n= 32	22.7 (37.3)	n=47	**0.01**
South (Petionville)	8.7 (11.4)	n= 22	10.3 (19.5)	n=29	0.74
West (Carrefour)	8.9 (11.3)	n= 18	12.9 (22.7)	n=28	0.48
Outside Port au Prince	5.0 (3.1)	n= 8	12.2 (31.2)	n=22	0.53

The difference between the delay for preeclamptic and normal participants was also assessed. Statistically significant longer delays for preeclamptic women were found for

two neighborhoods: East (including the Delmas neighborhood where the CRUO hospital is located), as well as downtown Port au Prince, which is the neighborhood adjacent to the CRUO hospital (see Annex 12).

Table 16 presents data on associations between participants' health history and their delay to accessing care. Only about a quarter (26.4%) of women in this study reported that they had previously visited a doctor. This same group, minus two participants, also reported having a history of a medical problem prior to the pregnancy. A history of a doctor visit or health problem prior to the current pregnancy was associated with longer delays among preeclamptic women only. A doctor visit, or a diagnosed health problem, may be indicative of more health care utilization prior to the current pregnancy. Participants who had more contact with health care providers also had longer delays (median 8.8 hours, IQR=23.4 for women with a history of a doctor visit versus 4.0 hours, IQR=7.8 for women with no doctor visit). The length of delay to access care in the current pregnancy was unrelated to other health history factors. For instance, even women who had a history of delivering at home, who might be expected to wait longer to come to the hospital, did not have longer delays to care in this study.

Table 16. Length of delay (hours) for preeclamptic and normal women by health history

Health history factor	Normal Group		Preeclamptic Group	
	Length of delay (n)[l]	*p*-value	Length of delay (n)	*p*-value
Previous doctor visit Yes	7.4 (44)	0.69	23.1 (63)	**0.02**
Previous doctor visit No	6.7 (145)		11.4 (167)	
Previous health problem Yes	7.3 (44)	0.74	24.0 (61)	**0.01**
Previous health problem No	6.7 (145)		11.4 (169)	
Preeclampsia yes[m]	9.8 (9)	0.45	13.2 (49)	0.80
Preeclampsia No	5.7 (92)		10.7 (65)	
Other previous birth complication Yes	5.6 (3)	0.95	8.1 (27)	0.64
Other previous birth complication No	6.0 (101)		13.0 (86)	
History of home birth Yes	4.8 (31)	0.39	8.2 (29)	0.42
History of home birth No	6.5 (73)		12.9 (86)	

[l] Survey participants were excluded who did not answer length of delay
[m] History of preeclampsia, birth complication and home birth calculated for multiparous participants

As seen in Table 17, most clinical factors affecting the current pregnancy, such as whether or not a woman received antenatal care, were not associated with delay among study participants. The exceptions were adequate antenatal care (four or more visits), which was associated with lower risk of delay, but only among normal women.

Participants also reported whether or not they had been diagnosed with preeclampsia during the pregnancy. Some participants who were not identified as preeclamptic by their MSF medical chart reported having been earlier diagnosed with preeclampsia (13 participants). These women experienced a statistically significant longer delay to access care compared to the rest of the normal women. However, this small sample was skewed by two participants who had total delays of seventy-two hours. An analysis of this subset of women shows that five of these thirteen women had a blood

pressure reading on admission to CRUO that could have been indicative of hypertension or preeclampsia. It is possible that some of these women who were categorized as normal may have actually had preeclampsia. However, blood pressure can be normally elevated just prior to delivery; and some of these women's elevated blood pressure may have represented a transient, normal elevation.

Table 17. Length of total delay (hours) by clinical risk factor and preeclampsia status

	Normal Group			Preeclamptic Group		
	Yes: length of delay (n)[n]	No: length of delay (n)	*p*- value	Yes: length of delay (n)	No: length of delay (n)	*p*-value
ANC with health professional	6.8 (185)	8.9 (6)	0.63	14.2 (225)	25.2 (8)	0.28
Adequate ANC (4+ visits)	5.9 (157)	10.2 (28)	**0.04**	13.6 (187)	15.3 (36)	0.73
Diagnosis of Preeclampsia this pregnancy	16.8 (13)	6.1 (177)	**<0.01**	13.1 (115)	16.3 (105)	0.70
Birth plan with health professional	6.8 (174)	6.9 (17)	0.97	14.9 (210)	10.7 (17)	0.84
Any preeclampsia danger symptoms remembered	9.4 (30)	6.4 (161)	0.15	16.4 (74)	13.8 (159)	0.45
ANC with TBA	7.9 (40)	6.5 (150)	0.46	13.4 (48)	14.9 (185)	0.75
Birth plan with TBA	6.2 (32)	6.7 (9)	0.84	14.0 (27)	17.0 (15)	0.71
Medications taken in pregnancy	6.9 (175)	6 (16)	0.73	14.5 (218)	16.8 (13)	0.89

[n] Survey participants were excluded who did not answer length of delay

Visits to health centers prior to admission at MSF were not associated with longer delays to access care (Table 18). In fact, visiting more than one health center prior to

MSF was associated with shorter delay to care among the preeclamptic group, although this association was not statistically significant.

Table 18. Length of total delay (hours) for preeclamptic and normal women based on behavioral risk factor

	Normal Group			Preeclamptic Group		
	Yes: length of delay (n)[o]	No: length of delay (n)	*p*-value	Yes: length of delay (n)	No: length of delay (n)	*p*-value
Visit to one health center prior to MSF	4.7 (58)	7.7 (132)	0.07	15.2 (115)	14.0 (118)	0.76
Visit to more than one health center prior	8.9 (9)	6.7 (181)	0.55[p]	7.2 (16)	15.1 (217)	0.27

[o] Survey participants were excluded who did not answer length of delay

[p] There is a statistically significant difference between these two groups (those who visited more than one health center, and those who did not) when delay is evaluated based on a dichotomous variable (long delay > 6hrs, not long delay) ($p = 0.03$)

We found no significant differences among total delays by transport method, with the exception of preeclamptic women who walked to the MSF hospital, who had a statistically significant longer total delay (Table 19). There were no significant differences in the second (transport) delay by transport method. Preeclamptic women had some differences in the transport they used versus normal women. Fewer women with preeclampsia used a private car (44.0% versus 60.8%, $p < 0.01$, data not shown). More women with preeclampsia walked to MSF (6.5%) than normal women (1.4%, $p < 0.01$, data not shown), and they had a longer delay to reach care. Use of ambulance services, public transportation, or motorcycles were not statistically different between preeclamptic and normal women.

Table 19. Length of total delay by transport method and preeclamptic or normal status

	Normal Group			Preeclamptic Group		
	Yes: length of delay (n)	No: length of delay (n)	*p*-value	Yes: length of delay (n)	No: length of delay (n)	*p*-value
Walking	2.3 (3)	6.9 (188)	0.46	28.1 (18)	13.4 (215)	**0.03**
Motorcycle	11.7 (12)	6.5 (179)	0.10	10.0 (12)	14.8 (221)	0.56
Public transport	6.4 (37)	6.9 (154)	0.77	13.9 (64)	14.8 (169)	0.82
Car	6.0 (117)	8.2 (74)	0.16	14.4 (105)	14.8 (128)	0.92
Ambulance	10.4 (21)	6.4 (170)	0.09	11.0 (32)	15.2 (201)	0.44

Risks for poor clinical outcomes- Maternal outcomes

Longer total delays were not associated with poorer clinical outcomes. (Table 20). There was a small, non-significant trend towards a relationship between longer delays and cesarean section (60.2% versus 65.4%, p=0.42) and ICU admission (7.5% versus 10.9%, p=0.37) among preeclamptic participants with long delays.

Table 20. Maternal outcome by length of delay for preeclamptic and normal women

	Normal Group			Preeclamptic Group		
	Delay < 6 hours: n[q] (%)	Delay ≥ 6 hours: n (%)	*p*-value	Delay < 6 hours: n (%)	Delay ≥ 6 hours: n (%)	*p*-value
ICU admission	1 (0.7)	0 (0)	0.45	9 (6.9)	11 (10.9)	0.28
Coma	no cases	no cases		1 (0.8)	1 (1.0)	0.86
Transfusion	1 (0.7)	0 (0)	0.45	5 (3.9)	2 (2.0)	0.41
Eclampsia	no cases	no cases		13 (9.9)	9 (9)	0.81
Cesarean section	7 (4.9)	5 (10.4)	0.19	80 (61.1)	66 (65.4)	0.50

[q] Survey participants were excluded who did not answer length of delay

Among participants in the preeclampsia cohort, women who experienced an eclamptic seizure were not more likely to have experienced a delay to care. In fact, the

trend, although not statistically significant, was towards shorter delay to care among women experiencing an eclamptic seizure. However, only twenty-three of the eclamptic participants (out of fifty-two in total) were included in the analyses of delay, either because they were withdrawn from participation (twenty-two women), or they could not respond to the question about either first or second delay. Many women who experienced an eclamptic seizure were unable to remember the events leading up to their admission at MSF, either because they had a seizure at home and were unconscious, or because they were experiencing memory loss secondary to seizures experienced at the hospital.

Delay and the risks for poor clinical outcomes: Neonatal outcomes

Longer delays to accessing emergency obstetrical care were not associated with poor neonatal outcomes (Table 21), with the exception of stillbirth. Measures of poor infant outcomes, including NICU (Neonatal Intensive Care Unit) admission, low birth weight, and low APGAR scores were unrelated to the length of delay for either the preeclamptic or normal groups. However, there were more stillbirths for preeclamptic women with delays less than six hours, as compared to preeclamptic women with delays of greater than or equal to six hours (14.5% versus 5.9%, $p=0.03$).

There were 30 total stillbirths in the study, 29 of which occurred to women with preeclampsia. Stillbirths were associated with women delivering at earlier gestational ages (32 weeks versus 37 weeks, $p<0.01$), indicating earlier onset and perhaps more severe preeclampsia. Additionally, stillborn babies were more likely to have low birth weight compared to the babies of all preeclamptic mothers (88.5% versus 46.2%,

p<0.01), which could also indicate more severe disease (data not shown).

Table 21. Neonatal outcome by length of delay for preeclamptic and normal women

	Normal Group			Preeclamptic Group		
	Delay < 6 hours: n[r] (%)	Delay ≥ 6 hours: n (%)	*p*-value	Delay < 6 hours: n (%)	Delay ≥ 6 hours: n (%)	*p*-value
NICU admission	18 (12.8)	9 (18.8)	0.32	52 (40.9)	44 (43.6)	0.69
Stillbirth	0 (0)	1 (2.1)	0.96	19 (14.5)	6 (5.9)	**0.03**
Low birth weight (<2500 grams)	22 (15.7)	5 (10.4)	0.35	65 (50.0)	46 (46.0)	0.55
APGAR <7 at 5 min	12 (8.5)	7 (14.6)	0.24	46 (35.1)	30 (29.7)	0.36

[r] Survey participants were excluded who did not answer length of delay

Summary of Quantitative Findings

Survey data indicates that many women in this study experienced long delays to access health care. Almost one fifth of preeclamptic participants experienced a twenty-four hour delay to access health care after their symptoms started. Very long delays among some preeclamptic participants were due to long first delays at home. Of participants who experienced long delays, there were few identified demographic, clinical or behavioral risk factors that were statistically associated. Most women in this study accessed antenatal care with a doctor or nurse, and received the recommended four visits. Many women and infants in this study experienced poor clinical outcomes. However, there were no statistical associations between longer delays and poor clinical outcomes.

CHAPTER 6: QUALITATIVE RESULTS

The quantitative survey results indicated that many preeclamptic women faced long delays in accessing emergency obstetrical care. Qualitative interviews offered a subset of the survey participants the opportunity to reflect on the process of seeking care, difficulties they encountered, as well as how they managed to overcome them.

Qualitative interviews were conducted with eighteen women, and eight family member representatives, who had experienced a long (>6 hour) total delay to access care, as previously described in Chapter Four. Although individual experiences varied by participant, many participants voiced common experiences, and identified additional common difficulties experienced by other Haitian women not identified in the quantitative results. The themes discussed here were identified using a grounded theory approach, as discussed in Chapter Four, which allowed the participants' own words and experiences to guide the analysis of the data. Themes have been organized into their effects on first, second or third delays to access care.

Overview: Survival Techniques

Interview participants explored themes surrounding the experiences and decisions of having complications of pregnancy, and seeking and finding health care. These women reflected on decisions to leave home, to travel to seek care, and to receive appropriate emergency care for their pregnancy problems. Participants used their knowledge, experience and community support to devise creative solutions to the challenges of leaving home, of transport to the hospital, and of finding appropriate medical care. In the words of one participant: "If you lack the technique to survive, you

can end up dying" (Interview 17). Both of these words: "technique" and "survive" encapsulate several overarching themes that emerged from the interview data. While the interview data was elicited in order to add insight into the understanding of delayed access to emergency care, in the women's own words and experiences, survival techniques were at the forefront. These themes wound through the experiences of the first, second and third delays, as women navigated around and created solutions to the obstacles in their way. These survival techniques influenced how the women and their families anticipated and reacted to obstetric emergencies, and the delays that resulted.

At home: the First Delay

Being sick, financial constraints, as well as the cost of health care, were themes raised by many participants that affected their decisions about when to leave home to seek care. God and participants' faith also played an important role in how problems were viewed, and the responses to those problems. Devising solutions—participants' "techniques"—were crucial to overcoming or managing these problems. Women and their families reflected on these challenges, and the solutions they devised, when describing how and when they decided to leave home.

Financial difficulties

Many participants faced financial difficulties. Several participants related experiences of extreme deprivation encountered during their pregnancies, including this 23 year-old woman:

> *I can barely take care of [my three children], and now I am about to have a fourth one... I think a lot when I'm pregnant, I think about if I die while giving birth how the other kids are going to survive. That's all. (Interview 10)*

Another preeclamptic participant, twenty-eight years old, recounted the difficulties she faced feeding her children: "Sometimes in the morning you don't know what your child will be eating. When you are a mother, you can choose to beg just for your kids" (Interview 17). Another participant described her precarious living situation: "I, myself, feel that I have a lot of problems. I was living under a tent, however now a good friend of mine gave me a small place to live, but that place has no roof" (Interview 4).

Other participants recounted financial worries that were less stark, yet still difficult: "I was the only one providing, there are things that you would want to eat or things that you would like that you can't afford" (Interview 15). This thirty year-old preeclamptic participant paid five hundred Haitian Gourdes (about $10 USD) to travel several hours from her village to Port au Prince and the MSF Hospital.

Financial difficulties were understood by one participant as an overriding problem for most Haitian pregnant women. This participant described the methods and systems that pregnant women must develop as "survival techniques":

> *Well, in Haiti, some women are really happy being pregnant. Many times, for others, getting pregnant is the worst thing ever, because things are really hard in this country. Sometimes, after telling your partner that you are pregnant, he might walk away, then you really don't know what to do, you have all kinds of problems. If you lack the technique to survive, you can end up dying of hunger. Life is really hard, it is so hard that someone should avoid getting pregnant. It will be better to have one or two children, but it is really not good for someone to have lots of kids with all the problems that can happen. (Interview 17)*

She explains the consequence of the lack of survival techniques in bleak terms: death from hunger. This quote encapsulates this woman's sense of desperation, as well as her

resilience and self-sufficiency.

A thirty year-old participant from the Petionville neighborhood explained the difficulty of pregnancy in Haiti: "There is no money, no work, you need to see the doctor every month, but to do so, and you need to have a job. This is why so many women ended up having miscarriages due to lack of care" (Interview 19). For this woman, financial difficulties translated into poor access to health care for Haitian women in general, whom she believed suffered pregnancy complications as a result. While this woman describes the difficulty of accessing antenatal care, the costs of emergency care are even higher, and likely even more out of reach for many women. Whereas survival techniques may gain a woman enough food to eat, perhaps they were not sufficient to overcome higher financial barriers to health care.

Many interviewees described financial pressure, and the struggle to have enough money, as a constant concern for them and the women they knew. With most women in Haiti living below the international poverty line, this experience is likely to be widespread. Deciding to leave home to seek care is also a financial decision, and one with which many participants struggled. Women in this study described overcoming struggles not only to find money for health care services, but also for the basic necessities of life, including food and shelter.

Role of faith, God

Decisions to leave home to seek care were also affected by women's faith. Many participants identified God as the primary agent in their health, both positively and negatively. This feeling was summarized by this thirty-two year-old preeclamptic

participant, who stated:

> *I did ask God to have a normal delivery, when I say normal I mean no C-section. But when God is working you can't tell him what to do. That means whatever God wants, it's what will happen" (Interview 21).*

This woman had a healthy baby by cesarean section after being referred from St. Catherine Hospital to MSF.

Many participants thanked God for being alive after a difficult pregnancy, such as the thirty-seven year-old woman who said:

> *I was ten days overdue and I still couldn't deliver the baby, my feet were swollen, I practically could not do anything. It was not easy, it was not easy at all but God saved me, and I thank God for that (Interview 7).*

From the perspective of these participants, God played an active and direct role in the mode and outcome of their pregnancy and delivery. What is not clear from the interviews, however, is how this faith may have impacted participants' decisions to hurry or to delay seeking health care. Quantitative survey data did not support an increased or decreased delay among religious women (data not shown).

One participant reflected on the role of finances and faith in delaying access to health care for pregnant women. The husband of a woman with eclampsia offered his perspective:

> *[F]or pregnant Haitian women we realize there is more than one problem. Eclampsia is the most important one. Day by day it gets worse and more, it happens more in the low class because they stress more, they think a lot about what they are going to do, just for the baby to survive. And most of the time they say they will let God take care of it. Like La Fontaine had said « Help yourself, God will help you. » They could have made the effort to go to the doctor but sometimes they cannot afford it, and they just hope that God preserves their life. (Interview 16)*

This participant referenced a popular quote by Jean de la Fontaine, "Help yourself and heaven will help you".[149] This participant seems to suggest that women delay seeking health care because of both financial constraints, as well as their hope and faith that God will help them. Additionally, this participant raises an important concept: that stress is the cause of eclampsia, which was echoed by several other participants. This couple traveled ten hours from another state in Haiti to reach the MSF hospital, passing by two other hospitals on the way. Their journey included several hours of transport on foot, on a stretcher.

Other participants described feeling little personal agency in controlling the outcome of their pregnancy or birth, or of being able to provide for their family.

> *I was thinking about how I will take care of the baby. The reason why, it's because the dad does not take his responsibilities. I am deeply thinking how I will manage to feed ourselves, how I will be living because I do not have anything at all. Thank God MSF was here. God always comes to the rescue, but it's really, really hard for me. (Interview 17)*

This woman describes being thankful for God (and MSF) in her life, especially because she cannot count on her partner or others for support. The lack of a sense of personal agency for her life likely affects decisions regarding when to leave home to seek care. Other participants described a nuanced relationship between their own actions and those of God. "I had to leave the house with her and take her to a hospital. I could not have saved her. It's the hospital that can do that. If everyone could take care of themselves then everyone could stay home, but after God it's the hospital that can save you, so I took her to the hospital" (Interview 13).

God may be viewed as the ultimate authority, but people themselves have to work hard to ensure their own survival, in the eyes of many of the women and family members interviewed. As the quote above illustrates, participants' faith in God may interact in a very personal way to either delay or facilitate care-seeking. While most of the study participants did not explicitly link their faith with the decision on when to leave home, the belief and faith in God's support may play a role in how these decisions are made in this context.

Cost of health care

Thinking, discussing and strategizing—i.e. devising "techniques" of how to pay for health care—were foremost in the minds of many participants. The ability to pay, or not, for emergency care was linked inextricably with the decision and the delay to seek care. Participants who went to other hospitals prior to MSF, or who did not know that MSF offered free care, may have been disinclined to seek care if they felt they could not afford it.

One participant explained this dynamic:

> *[The private hospital staff] had asked how much money I had on me. I had 1500gdes, but they told me that I had to pay for the medication, therefore I told them that I didn't have all that money. I told them that I only had 750gdes with 1500gdes, so a total of 2250gdes. If I have to buy medicine, I would not have enough if I needed to buy an IV, and any other things, so then they transferred me here. (Interview 18)*

Despite leaving home and traveling to this emergency obstetric hospital, this twenty-three year-old woman experienced a long third delay as a result of being denied emergency services due to her lack of financial means. At the time of these interviews, the exchange

rate between Haitian Gourdes and US Dollars was about 45:1, so this participant had the equivalent of about fifty US Dollars to spend on his wife's care, which was not sufficient for her emergency treatment. This woman had an eclamptic seizure, and delivered a stillborn baby after being transferred to MSF from another hospital.

As the previous quote illustrates, the cost of treatment was identified as a major limitation to the ability to access care, and one that was repeated by many participants.

> *Interviewer: Did you find healthcare while you were pregnant?*
> *Interviewee: No.*
> *Interviewer: Why did not you go see a doctor or a midwife?*
> *Interviewee: Because I did not have the means, the possibilities.*
> *Interviewer: You did not want to go, or did you want to go, but did not have money to do so?*
> *Interviewee: I did not have money to do so*.
> (Interview 17).

For this participant, even the cost of antenatal services, which are typically much less than delivery services, was still a barrier to receiving health care.

The cost of healthcare was also identified as a major source of family stress.

> *When I was ready to give birth some people told me that the hospital charges for a C-section 20 000 gourdes and the normal delivery was 7 500. [My partner] was really worried about all that, and sometimes he would leave me in the house for the whole day by myself. Until I told him that MSF does not require for you to pay, that other hospitals maybe, but not MSF. At the beginning he did not believe me. He was still bothered with this situation because he did not have all this money that they told us we would have to pay. So, I came to the hospital without him knowing and I called him while I was there to tell him that I was at the hospital and that it's free, that is when he believed me and started coming more often and was standing by me (Interview 14).*

For this woman, pregnant with her third child, the prohibitive cost of health care, about four hundred and fifty US Dollars for a cesarean section, created distance from her partner, whom she felt was worried about paying hospital fees. She interpreted his

absence as worry about paying these fees, and saw that he returned to be with her as soon as the free care of MSF was known. This participant had a severely high blood pressure of 220/100 on her admission to the MSF hospital. She received a cesarean section, and both she and her infant did well after surgery.

The high cost of medical treatment led some participants to believe that their diagnoses were a way for their providers to make more money.

> *Some private doctors will tell you to eat certain type of food, or give you some specific medication. It's only so they can make money off you, these medications are most of the time for the baby to grow very big, like that they have to do a C-section…[What kind of medications?] Some kind of big pills, vitamins, very big pills, so the baby can get bigger in the stomach, the person also gets swollen so when you get to the hospital the doctor usually say that the baby is too big and that she will not be able to push the baby, therefore the doctor has to proceed with a C-section. And if you deny the C-section you will die. A lot of time they tell you that the baby is very big and it's not true, sometimes it's twins that you are carrying. (Interview 15)*

Cesarean sections typically cost many times the amount charged for a vaginal birth (reports vary, but typically many hundreds of US Dollars for cesarean section, versus about one hundred US Dollars for a vaginal birth), and are very expensive for most Haitian women. This participant's experience reflects not only the high cost of health care, but also many women's mistrust of medical providers, and the seeming contradiction between profit from medical services and the well-being of the patient.

The cost of health care was a clear barrier to accessing obstetric care for many respondents, and likely contributed to delays in seeking emergency care when needed. Given high costs of delivery, in particular for cesarean section, many women were wary of needing this operation given the price they would likely pay. With cesarean section

being an important treatment modality for severe preeclampsia, the women in need of this lifesaving treatment may not be able to access it due to financial constraints.

Interpreting their symptoms

Women described the symptoms that preceded their decision to leave home to seek health care. This twenty-three year old participant having her second baby described feeling sick prior to leaving home:

> *I was sick, all my body was swelling up, and I did not worry too much about it. Then on Thursday, I went to see a doctor. There they realized that my blood pressure was high, and the doctor told me to quickly go to the hospital. I have been sent here by Santo 17, and then when I came here, I had a C-Section...*
> *Interviewer: What did you do when your body started to swell-up?*
> *Patient: I really did not worry about it too much, because when I got pregnant with my first child my feet were swollen, but when I realized that my feet and my body were swelling up I decided to go to the doctor. They advised me to come to MSF and they also told me not to waste time because I could lose the baby due to my blood pressure being too high. I needed to have a C-section done right away.*
> *Interviewer: What did you think [was the problem] when your body started to swell?*
> *Patient: I used to get upset quite often, I thought that was the main cause of it. (Interview 4)*

This woman reported a twelve-hour first delay prior to leaving home. She attributed her stress, and being upset, as the cause of her edema. Her blood pressure was severely elevated on admission, and she had a cesarean section. Her baby had low APGAR scores and was admitted to the NICU.

Another participant, twenty-five years-old, reported her experience of preterm labor:

I started having some belly aches. I was like "wow," I have to go to the hospital, but the pain went away and I had some vegetables left to sell, so I went home after. When I got home I felt the pain again but this time it did not hurt much...I touched my stomach and I didn't feel the baby move. The next morning I woke up with no pain, but in the afternoon I felt the pain again and still no movement from the baby, so I waited for my husband to come home. He came home around 8pm and I asked him to take me to the hospital. When I got here, they consulted me, but didn't say anything to me. I was given a shot and also was put on an IV. I was transferred to another room, then suddenly I started feeling hot, very hot. I was about to give birth. They passed a machine on my stomach, I was laying down and was told to push, and when I pushed the baby was still born.
Interviewer: Do you understand what happened with the baby?
Patient: No, I don't understand because when I went to the hospital [for antenatal care] they told me my blood pressure was 120/80 [normal]. They also gave me some pills to drink. I did drink some but didn't drink all. I also had a few infections, but on the 5th month I started swelling up and each time I've gotten pregnant in the past it was always like that. And I had said to myself that next time I get pregnant again, I would like to have enough money to see a private doctor. Like that, the doctor will remove the baby at the right time. (Interview 5)

This patient, having her third baby, reported having symptoms of preterm labor for a day prior to seeking care. However, she reported a first delay of four hours on the quantitative survey. She described here that her need to sell her vegetables, as well as to wait for her husband, impeded her ability to leave home to seek care. This patient reports a history of "swelling" with each pregnancy, which could indicate a previous history of preeclampsia with her other deliveries. This woman also reported that she could not access the hospital closest to her home because it was too expensive. She delivered a stillborn, very preterm baby.

These women report feeling pain, or feeling sick, and dealing with their symptoms by themselves, at home. Only after the symptoms persist, or worsen, do these

women decide to leave home and see and doctor. The woman who suffered a stillbirth explicitly links her financial situation to her poor outcome, and reports that her wish is to have enough money to afford private care, which she believes could help her deliver a healthy baby.

Impressions of high blood pressure

In addition to their symptoms of pain or edema, women reflected on theirs and their doctors' views of high blood pressure that led to their admission at MSF. As all of the interview participants had preeclampsia, many of them discussed the experience of having high blood pressure. Many participants saw high blood pressure as a normal experience for themselves: "Every time I give birth, my blood pressure always gets high but always returns to normal after delivery", said this thirty-seven year-old preeclamptic woman having her fourth child (Interview 10). Another participant stated that during her pregnancy "The problem I had was that every time they would take my blood pressure they would tell me that it was high but I didn't feel anything was wrong" (Interview 21). With high blood pressure seen as a normal part of pregnancy, participants might be unlikely to realize the danger of worsening high blood pressure, perhaps increasing the first delay in these situations.

Another patient described the treatment offered by her doctor when she was diagnosed with high blood pressure:

> *Interviewer: How did you manage your high blood pressure? What did you do?*
> *Patient: I took some high blood pressure pills. It went down, when I got here it was 150/100...*

Interviewer: The doctor prescribed you some pills; did he explain to you the risks with high blood pressure?
Patient: He told me not to worry too much, however the blood pressure stayed high.
Interviewer: Did he give you a follow-up appointment?
Patient: No.
Interviewer: Did he prescribe you any medicine? Did you stay at home?
Patient: He did not give me anything.
(Interview 19).

This woman's experience reveals a lack of provision of standard of care and follow-up for hypertension in pregnancy. It also reflects the beliefs of several participants in this study, that high blood pressure is caused by "thinking too much" or "worrying". Other cases of healthcare providers instructing women to "not get upset" were also noted. One patient described that her doctor did not discuss her high blood pressure with her: "The doctor told me not to eat too much salt, and try not to get upset" (Interview 22).

The belief that stress was a cause of high blood pressure was echoed by other participants. "The stress is a major problem, sometimes [women] get angry, it's not that they want to get angry, but they can't help it. They don't see how tomorrow will get better so they get upset, and that causes the eclampsia" (Interview 16). Another participant explained that her high blood pressure and "eclampsia" were due to family stress:

Patient: I was about 8 months when I started having problems with some of my mom's family, that's when my blood pressure started getting high. So I went to the doctor when I turned 9 months. I was told that my blood pressure was 200/110, they told me to be very careful that I could have an eclampsia attack. And when they checked it was exactly that...
Interviewer: Did they explain to you what is high blood pressure? What did the doctor say?
Patient: He did not tell me anything.
Interviewer: So, how did you understand what it was?

Patient: I did not understand it; I just told myself that stress was the cause of the eclampsia attack. (Interview 19)

Of note, this participant had preeclampsia, but according to her chart at MSF, did not suffer an eclamptic seizure.

Another participant reported a similar experience with family stress: "My parents did not make it easy for me; they ended up making me very stressed, and even caused some type of eclampsia that I did not even know about. Everybody saw me swelling up, and I had headaches all the time" (Interview 8). This twenty-one year-old patient, who was living with her parents at the time of her admission, was also diagnosed with preeclampsia (not eclampsia) and delivered preterm after admission with a blood pressure of 170/120. It seems from these quotes as though there was a lack of distinction made between preeclampsia and eclampsia, which may reflect an overall lack of knowledge about these problems.

Interview participants also described their medical providers' perceptions of high blood pressure. One woman described what happened when she was diagnosed:

So, I went to the clinic to see a doctor; no, not to see a doctor but to do a proteinuria exam that came out negative. However, the doctor advised me to stay at the hospital because of my blood pressure being high. So, I stayed, and sent someone at home to get everything I needed, and they kept me under medications, but it never got better. On Sunday night, they checked me again, and the blood pressure got higher (Interview 6).

This woman reported that she was kept in the hospital once her high blood pressure was discovered, and was given medication, tested for protein in the urine (a sign of preeclampsia), and monitored. Her blood pressure was severely elevated when she arrived at the MSF hospital, but she delivered a healthy infant and did well postpartum.

Another woman described a similar process: "I was sick, all my body was swelling up, and I did not worry too much about it. Then on Thursday, I went to see a doctor there, they realized that my blood pressure was high, and the doctor told me to quickly go to the hospital" (Interview 4). This woman also had severely elevated blood pressure, and her infant was admitted to the NICU. Delays to accessing emergency care were minimized in these cases due to prompt diagnosis and referral.

Other participants described a less-intensive, and more delayed process:

> *Patient: Every time I would go [to the doctor], he would tell me that my blood pressure is high, and sometimes when I went back the blood pressure got higher.*
> *Interviewer: What did the doctor give you for that?*
> *Patient: He never used to give me pills, he used to prescribe me a small pink pill, and iron syrup.*
> *Interviewer: He did not give you pills for the blood pressure?*
> *Patient: He never gave me pills for the blood pressure, he just told me not to take in too much salt.*
> *(Interview 24)*

This woman describes a dangerous situation that seems perceived as much less serious by her doctor. She describes having high blood pressure at each visit, yet was not given medication, testing, follow up, or appropriate counseling about the risks of her condition. She goes on to report that the doctor gave her a follow-up appointment once per month (Interview 24). This woman's doctor did not perceive her high blood pressure as a problem to be addressed immediately. This participant lived in Cite Soleil, one of the poorest neighborhoods of Port au Prince, where she first visited the local MSPP hospital. She went on to deliver preterm at MSF, after being admitted for severe preeclampsia at eight months gestation.

Other participants also described being diagnosed with high blood pressure in an outpatient (antenatal care) setting, and not being referred for further treatment:

> *Interviewer: During your follow-ups did they notice that your blood pressure was high?*
> *Patient: Mmm…mmm*
> *Interviewer: What did they do when they realized your pressure was high?*
> *Patient: Nothing, they only gave me two pills.*
> *Interviewer: Do you know what they were?*
> *Patient: No, I do not know the name; they just gave me two pills.*
> *(Interview 21)*

This participant describes an apparent lack of concern or urgency on the part of her medical provider when faced with a potentially dangerous situation. In this case, this thirty-two year-old primiparous, preeclamptic patient visited three health centers when she was in labor before being admitted to MSF. The sense of urgency, or not, on the part of medical providers might have had an impact on the decision of when to leave home to seek care. Some women were referred directly to the hospital from antenatal care, limiting their delay, while others were left to make their own decisions about how to respond to their symptoms.

The experience of eclampsia

Participants in this study described harrowing experiences responding to and finding treatment for eclampsia. Many of these experiences were described by family members who witnessed an eclamptic seizure and struggled to respond to it. Other family members described transporting women having eclampsia, or finding health care for a family member who was suffering from eclampsia. Family members described intense scenes of finding a family member in the midst of an eclamptic seizure: "I turned

on a flashlight and saw her on the floor foaming and bleeding in the mouth, her body stretching on the floor" (Interview 12). Another participant described their experience:

> *[O]n Friday around eight pm she started complaining of a stomach pain. Around ten we made her some oatmeal but she could not eat it, and all of a sudden she passed out. We automatically called a taxi motorcycle to take her to the hospital in Croix des Bouquets. When we got there she was unconscious, they immediately transferred her here. She was still unconscious, she was already having an eclampsia attack, and until now all the inside of her mouth is still sore from all the biting. (Interview 15)*

Another family member described the experience of witnessing a woman's eclampsia attack.

> *We did not think it was a seizure she was having. We just heard the screaming, and she screamed louder and this time her cousin said that it is an eclampsia attack that she was having. (Interview 9)*

Family members in this scenario did not appear to understand the cause of the woman's screaming, until a cousin recognized the symptoms. One mother described the experience of trying to help her daughter, and then watching her have a seizure.

> *She was sick; she told me she had a headache, so I went outside to get a bag that had her medications... [A]ll of a sudden I heard a loud noise like something that fell. I called a guy named Jean-Baptiste, and I asked him what fell and that's when he told me that it was my child that fell. She was trying to get off the bed and she fell. She was grinding her teeth; I've never seen anything like that before. (Interview 18)*

Family members who witnessed these eclamptic seizures and their aftermath spoke of the difficulty of watching their loved ones suffer, and the ensuing search for medical care. The fact that these participants experienced eclamptic seizures at home reflects a

breakdown in the system of antenatal care, which aims to identify patients at risk, and prevent these potentially deadly events.

Second Delay

The second delay, and the process and techniques that the participants used to negotiate transport were described by many participants in the interviews. The decision of where to seek care, finding ways to avoid heavy traffic, and the role of community supports were all key themes that emerged in participants' experiences of the second delay.

Coming to the MSF Hospital

The choice of where to seek care was one of the key decisions faced by women leaving home and seeking emergency obstetrical care. For some patients, they chose to come directly to MSF. Others were referred by other hospitals or doctors. For some patients, they were turned away at other sites, and eventually made their way to MSF. With several state maternity hospitals, as well as multiple NGO hospitals and clinics and private hospitals, pregnant women in Port au Prince have a variety of options. The decision regarding where to go to seek care can have a momentous impact on the type of care given, the cost of care, and the delay to receiving appropriate care.

Some participants described seeking care at a structure that was found to be closed. As one twenty-seven year-old primiparous patient's family member described,

> *We waited for daylight [after series of eclamptic seizures] to call a taxi. I explained the situation to the taxi driver and he agreed to take her to the hospital, so we went to a maternity clinic. But when we got there they told us that the clinic was closed. (Interview 12).*

By the time this participant arrived at MSF, after visiting both the General Hospital and the national maternity hospital (Maternité Isaie Jeanty), her blood pressure was severely elevated at 190/140, after suffering eclamptic seizures. She was admitted to the ICU (Intensive Care Unit), and was comatose at the time of the interview. Her baby had been admitted to the NICU (Neonatal Intensive Care Unit). In this situation, the delay to access care was affected not only by the extended second delay due to the closed maternity clinic, but also by the longer first delay due to the decision to wait until daytime to leave home.

For some participants, the events that led to their admission to MSF seemed entirely out of their control. For example, the family member of a twenty-three year-old having her fourth baby and suffering eclamptic seizures described a series of hospital visits and referrals based on security concerns, financial difficulties, and housing:

> *I called on the neighbor for help. We got two motorcycle taxis that took us to a hospital in Arcahaie where she got the emergency care that she needed, but the doctor told me that she could not stay there. They wanted to transfer her to a hospital in St. Marc but instead I requested that I go downtown to St. Catherine, only because I knew that it was where I was planning on taking her and that I have my sister that doesn't live too far- I could easily sleep at her house. On my way to St. Catherine there was a lot of shooting, it was the police shooting and they made me go to a private hospital where I had to pay for every service I got. I explained to them that I did not have much money. I only had 750gdes so they gave her some first aid than they called an ambulance to transfer her to MSF (Interview 18).*

Despite receiving adequate emergency care at the first hospital visited, the patient was not allowed to stay at this hospital and was referred by her doctor, who did not ensure transport to another facility. Knowledge of various hospitals allowed this family member

to request transfer to a hospital near where they could stay, but which put them at risk for violence (St. Catherine Hospital is located in a neighborhood of Port au Prince with a history of gang violence). Even the third choice hospital was out of reach financially. Finally, the patient was transferred to MSF. Her baby was born stillborn.

Women described situations in which referrals to MSF from other structures had been organized, as in the previous example where the private hospital called for an ambulance. In other cases, women were simply given a referral letter and asked to proceed to MSF on their own, for example, the thirty-seven year-old preeclamptic participant who stated "It is the doctor that gave me a paper and told me to come straight here" (Interview 7). This woman reported that it took her two hours to arrive at MSF from the referral hospital by private car.

A thirty-two year-old preeclamptic woman having her first child described the lack of appropriate care she received at the first hospital she visited:

> *[W]e went to St. Catherine on Sunday in the afternoon around 4pm. There was no light; I fell asleep in the dark. They did not even turn on the generator. Imagine dealing with this pain and with mosquitoes at the same time. Monday morning, I was still in pain and it was when everyone was leaving their shift that I was told that I could not stay there. I felt like they were all going to leave, and leave me here, but they saw urgency of my case they transferred me here. I don't think this place [St. Catherine] was a hospital. There were two nurses present at the time I got there, and you know when you are somewhere you can find someone to talk to you while you are waiting, but not one person spoke to us. They did not even start an IV line for me. Nothing was done except when my blood pressure started going up, they gave me two pills to help bring it down. That's all until I was transferred here. (Interview 21)*

This woman felt disregarded by the medical staff, who did not provide what she felt was appropriate care. When the staff were leaving, they arranged to transfer her to MSF. The

hospital staff had a medical staff transport bus that dropped this patient off halfway to MSF; she reported having to find two taxis after that to bring her to the MSF hospital (Interview 21).

Another participant, the sister of a thirty-three year-old multiparous patient with eclampsia, described a series of visits to several MSPP hospitals around Port au Prince:

> *On Thursday, I saw her on the ground foaming at the mouth and seizing. I went to the maternity clinic in Carrefour. They did not want to see her. I went to the General Hospital, they could not receive her due to overcrowding. Therefore, I went to Chancerelle [MoH facility in Port au Prince]. There, they took charge of her; the doctor went and got her medication although I had not yet paid. They gave her oxygen right away and a lot of medication like magnesium sulfate to get rid of the seizure...I also asked about the baby and I was told that the baby was doing well and that the heart beat is steady, that they were getting ready to transfer me to MSF. There she will have a C-Section done (Interview 3).*

Delays to receiving emergency care, crucial at the time of an eclamptic seizure, were lengthened due to closed hospitals, overcrowding, and a lack of capacity to handle emergencies. Unfortunately, the family members' decision to seek care at a hospital that was closed, and one that was overcrowded, led to longer delays than if they had decided to go straight to MSF.

This family member was angry at the experience of being turned away from the General Hospital [a MSPP hospital] despite the fact that her sister was having an eclamptic seizure in front of the maternity center:

> *The entire problem I had, I think it is because the health care system is missing something. A hospital should never refuse to treat a patient, especially a pregnant woman who is having a seizure. If she had died I would have stoned the general hospital (Interview 3).*

This woman echoed themes of distrust and anger towards the medical system. This participant also self-identified the problem of delay to care, and the negative effect this had on her family member, who could have died as a result. This family visited four other hospitals prior to arriving at and being admitted to the MSF hospital. The patient had three eclamptic seizures before admission, and her blood pressure was 180/120 on arrival. She was admitted to the ICU, and her newborn was admitted to the NICU. They were both still in intensive care at the time of the interview.

Urban congestion and traffic

Unique to the experiences of urban pregnant women, traffic can significantly lengthen the second delay to access emergency obstetrical care. Port au Prince has substantial urban congestion problems, where even short distances can be delayed by gridlock, poor road conditions, and the need to avoid unsafe neighborhoods.

The family member of an eclamptic patient recounted their experience getting from Petionville to Delmas, the neighborhood adjacent to where the MSF hospital is located.

> *On the way to Petionville, she started having a seizure, everyone in the street told us to take her by car. So, we rented a car to take us here, but on our way there was a lot of traffic, therefore the driver had to take some shortcuts until we got here (Interview 9).*

Avoidance of the most direct route and the ensuing traffic jams between Petionville and Delmas is common; unfortunately, the "shortcuts" rarely result in substantially shorter arrival times.

Other people managed traffic by calling an ambulance.

> *[F]or sure the ambulance is way better than a private car, because even during heavy traffic, the ambulance will get by easier, whereas, the bus takes longer. The ambulance is always faster. (Interview 13)*

The ambulance's ability to navigate through traffic was a major advantage to this method of transport. However, other participants indicated that the ambulance was not always available when needed. "It's very difficult when you call for an ambulance, and they tell you the ambulance is not working. It's an emergency transport, it should be working" (Interview 16).

Role of the community

Many participants spontaneously identified community members (as opposed to family members) as crucial supports for or hindrances to accessing emergency obstetrical care. Many women reported relying on community members to arrange or facilitate transportation at the moment of the emergency. "We came in a private car; my husband has a friend who owns a car. He had asked him to take me, and the friend did" (Interview 7). Other participants relied on the spontaneous advice of community members when deciding where to access health care. For example, when asked why she decided to come straight to MSF, a family member of a twenty year-old preeclamptic patient responded, "The reason why we came here, it's because while driving through the shortcuts [to another hospital] some people advise us to come to MSF. And when we got here they took care of her right away" (Interview 9). This point also touches on the impact of urban congestion and traffic on the delay to access health care.

Community members were also crucial means of financial support at the moment of the emergency. The husband of a thirty year-old preeclamptic woman having her third child described how he was able to find the means to purchase needed medications during his wife's obstetric emergency:

> *Once I got [to the hospital], they gave me a prescription to fill, I had to make lots of sacrifices. I even asked some friends to lend me some money in order to purchase the medicines. If I did not do that she would have not received any healthcare whatsoever. It was a list of medicine like: magnesium, ringer lactate, catheter, presoline [antihypertensive medication], methyl, syringe (Interview 2).*

With few financial means available, people rely on the generosity and reciprocity of their families and community members to raise needed funds.

Traditional birth attendants, known as "*matrone*" in Haiti, were also important community supports for women. One participant answered affirmatively when asked whether she had seen a *matrone* for antenatal care:

> *Interviewer: How was the consultation with the matrone? How many times did you see her?*
> *Patient: I saw her three times, and the baby was not in the right position.*
> *Interviewer: What do you think of the care that the matrone provided?*
> *Patient: She massaged my belly; put the baby in the right place…. Then she told me to go see a doctor.*
> *(Interview 4)*

Some women in this study used *matrones* as an adjunct to the medical care they received from trained providers. They described seeing a woman who was present in their neighborhood, who offered reassurance or referral to the hospital. The family member of a twenty-two year-old preeclamptic woman described the experience of seeking care

from the local *matrone*:

> *[The matrone] soaps her belly; she really pays attention to details. She has her own medical box, but due to the fact that I met her on the street, she did not have time to go get her box. As I said we met on the street, she came, washed the belly, after the washing [the matrone] said that [the woman] is in labor, and everything looks good. She might take some time, but everything looked ok for a perfect delivery...She told me not to stay here with her; she encouraged me to take her to the hospital. (Interview 13)*

Despite the fact that the *matrone* told this family member that the birth would be perfect, she also referred this family to the hospital. This woman suffered three eclamptic seizures and was admitted to the Intensive Care Unit.

Sometimes community members also seemed to present hindrances rather than help. In one case, community members advised one person to keep her family member who was having eclamptic seizures at home. "[S]ome people also told us not to worry about it because she was like that with her other pregnancy, she always had seizures and that's when you usually go to the hospital; there is really nothing they will do to help, but I said no. I'd rather have her at the hospital than home" (Interview 9).

A thirty-three year-old preeclamptic woman pregnant for the fourth time described her experience with recurrent pregnancy loss, which led her to move based on her negative community experiences. "I moved because I wanted to have this baby. They used to make so much fun of me because every time I got pregnant I ended up losing the baby. I did everything to leave that place" (Interview 23). This woman delivered a premature baby, who was doing well at the time of the interview.

The interconnectedness of community was explained by one interviewee, who

was asked if he had to pay the people helping him and his wife: "No, these people were people from the community. They are our neighbors, they were just helping because today it's me that needed the help, and tomorrow it could be them. This is how we help each other" (Interview 16). With little public information on the availability of emergency care, and with few financial resources, people in this study relied on community and family when deciding where to seek care, and finding resources to pay for care.

Third Delay

Gratitude to MSF

Many participants echoed themes of gratitude for the quality and affordability of care they received at the MSF hospital. After experiencing delays at other facilities, or en route to the hospital, several participants noted that they were treated immediately upon their arrival to CRUO.

This thirty-seven year-old, who traveled from outside of Port au Prince, stated:

> *I came [to MSF] because I had a private car, even though I was in a lot of pain but God made it happen. And once I got there they took care of me right away. (Interview 7)*

The family member of a twenty year-old with preeclampsia echoed a similar sentiment: "As soon as the triage nurse saw her she took her inside to another nurse, she was taken in a room, since she's been in there, I have not seen her yet." (Interview 9)

In addition to minimizing the third delay to receive appropriate care, other participants also noted specifics about the quality of care from the MSF hospital. The

family member of a thirty year-old woman who had traveled from a rural area outside of Port au Prince stated:

> *The service is good; if it was not good she would have died because when she got here she was unconscious. They had to put her on oxygen, and a couple of IV's. I think she received really good care here. The only problem I encountered was that they do not want food to come in from home. Beside that the service was excellent. I don't think I would find services as good as I got at MSF at any other hospital. (Interview 15)*

Another participant, a twenty-nine year old woman who identified as internally displaced, echoed the same themes of quality medical care:

> *I wanted to give birth here because you get better care. I think the doctors are better, the way the hospital is functioning, it's cleaner, so that's why I like it, it is better. In total I had 3 C-sections here, and I love it. (Interview 14)*

This participant mentioned the cleanliness of the hospital, in addition to the quality of the medical staff, and the functioning of the hospital.

Affordability of care at MSF

With financial barriers and poverty being major stressors for many participants, the availability of free care at MSF was highlighted by many. Participants who mentioned this free care also linked it with the quality of care. Whereas charging for services seemed to be linked with distrust of other hospitals, participants seemed to trust the MSF hospital more for having no fees.

The feeling of gratitude to MSF for not charging fees was stated by this participant who said:

> *When someone has a C-section, some hospitals will over charge you, but here it was not much, you guys need a round of applause. Really, I would like to thank you for the good work that you guys are doing here. (Interview 13)*

This twenty-two year old woman paid 1 250 Gourdes (about twenty-eight US Dollars) to travel to the hospital, while suffering an eclamptic seizure. She and her baby were both admitted to the intensive care unit.

In the words of another participant, a twenty-nine year old woman:

> *What I would like to add, the care and compassion I received really made me feel better. MSF is helping a lot because there is a lot of people that cannot afford to pay 70 000gdes for a C-section and 50 000 gdes for normal delivery, therefore this project really came in handy. (Interview 14)*

This woman had a cesarean section, after being admitted with a severely high blood pressure. She describes the medical care at MSF as caring and compassionate, as well as being financially accessible. This participant, and others, reflected on the difficulty of paying high prices for medical care at other facilities, and wondered what would happen to the many women that MSF served if the CRUO hospital were not there.

Summary

Interview participants reflected on their experiences negotiating the first, second and third delays. The range of constraints that they faced, from economic to urban congestion, was matched by the creative and hard-fought responses they brought. Some participants used their knowledge to avoid or to shorten delays, while others reflected concern or anger over the problems that compounded the health issues they faced. This

qualitative data complements the findings from the quantitative survey, and adds rich nuance to the experience of seeking and finding emergency obstetrical care for these women. For instance, interview participants explained how the understanding of their symptoms, and the financial difficulties they faced, led them to stay at home for many hours prior to seeking care, adding to the understanding of long first delays identified in the quantitative data. Despite reported shorter second delays in the quantitative data, interview participants described difficult journeys on foot, through traffic, and via many other health centers, to finally arrive at MSF.

The "technique" to survive that was evident in the interviews related to themes of using community supports, of overcoming financial difficulties, and of choosing a hospital for women's care. "Survival" for these patients meant identifying and responding to high blood pressure and eclampsia, hoping that God would help them negotiate the myriad obstacles in their way. Together, survival techniques describe the preoccupations and decisions of Haitian women struggling to care for themselves and their families in the context of poverty, and in the face of life-threatening medical conditions. Life for these Haitian women was not guaranteed; they were actively involved in finding ways to help themselves overcome the many obstacles they faced.

Both interview and survey data suggest that participants' major challenges included economic hardship, access to quality health care, and difficulty navigating the Haitian health care system. Moreover, the stories of interview participants who faced long delays highlight the extremely dangerous medical situation of preeclampsia and eclampsia for both mothers and babies.

Quantitative and qualitative data indicate that the participants' decisions about where to access health care, and how to manage high blood pressure and eclampsia, had important implications for the experience of these participants, and the delays they encountered before receiving appropriate treatment. While some women reported receiving assiduous follow-up and referral services, others describe hospitals and health care providers that were much less intensive.

In a setting in which they themselves were sometimes the only one aware of, and responsible for, their healthcare, these women were forced to take the responsibility for their healthcare upon themselves. In the interviews, many women reflected on this feeling of autonomy—noting that Haitian women have to be able to take care of themselves, as there is no one else to help them. Almost all of these participants had received antenatal care, and most of them saw their antenatal care providers at least four times. Medications of some kind were prescribed, and birth plans were discussed. For many participants, however, it was their own decision, sometimes with input from family and friends, that led them to seek emergency care. Negotiating these decisions, and finding the strength and means to do so, posed enormous challenges.

CHAPTER 7: DISCUSSION

Summary of Essential Findings

This study aimed to quantify delays to care among preeclamptic women presenting at the MSF CRUO emergency obstetric hospital in Port au Prince, Haiti and identify predictors of these delays, as well as the clinical consequences of long delays. The goal was to use this information to make recommendations about how to reduce delays, and in turn hopefully reduce neonatal and maternal morbidity and mortality in the Haitian setting.

Past studies examining the Three Delays model of maternal mortality have identified several factors that have affected delays in other contexts, including distance to facility, cost, educational level, status of the woman in the family, perception of the gravity of the situation, transportation options, distribution of facilities, and the perception of quality at the facility.[67,70,71,74,76,77,80,81,86,89,90,93,102,138,150–160] However, relatively few studies[80,90,155,161] have examined how women in urban contexts access emergency care, and the specific delays they may encounter. This study helps to clarify the relative importance of the factors that are associated with increased delay to access emergency obstetrical care for urban Haitian women.

A subset of preeclamptic women in this study had significantly longer delays to access emergency obstetrical care than normal women, with seventeen percent experiencing delays of more than twenty-four hours. Median delays were much shorter, with a median total delay of five hours for preeclamptic women, and four hours for normal women ($p < 0.01$).

Longer delays for preeclamptic women were due to longer delays at home prior to deciding to leave and seek care at the hospital (first delay). Preeclamptic women waited an average of thirteen and one half hours after symptoms developed to make the decision to seek care. Third delays were also significantly longer in this group (fifty-nine minutes in the preeclamptic group versus thirty-eight minutes in the normal group). Second delays, or transport delays, were comparable in the two groups.

Quantitative results also found that few of the behavioral, clinical or demographic factors we measured were associated with longer or shorter delay for women in this study. Contrary to expectations, preeclamptic women who had a history of a health problems or doctor visits had longer average delays than those who did not. One could expect that more familiarity with the health care system would lead to shorter, rather than longer, delays. However, other published studies[152,162] indicate that women who have a poor opinion of health providers or facilities are more likely to delay seeking care.

There were no demographic factors that were found to be associated with longer delays in this study. The study had hoped to be able to identify the subgroups of women who were more likely to experience delays - whether by neighborhood, or age. These results do not suggest that there are clearly identifiable subgroups of preeclamptic women who are more at risk for delay- but also that almost one fifth of preeclamptic women experienced delays of more than twenty-four hours. Of the subset of women experiencing a twenty-four hour delay or longer, demographic indicators were similar, with the exception of economic status, where a smaller proportion of women in the very long delay group reported "doing well" or "good" economic status.

Despite the fact that the vast majority of women reported seeing a trained health professional (doctor, nurse or midwife) for antenatal care, a substantial minority also reported having antenatal visits with a traditional birth attendant. Twenty-one percent of women who received antenatal care from a doctor, also saw a traditional birth attendant for care. Qualitative interview data indicated that women accessed care from *matrones* who were neighbors, and who were accessible to come to women's houses as needed for a consultation. Women's experiences with possibly poor quality antenatal care from trained providers also could have influenced their decisions to seek additional care from locally available *matrones*. Women may not have felt satisfied with the quality of care they received from the doctors and nurses they saw, leading them to seek out other providers. Evidence from other studies[163] shows that poor perception of quality or poor treatment by medical providers may motivate women to seek care from traditional birth attendants.

The qualitative portion of this study explored the barriers to accessing emergency obstetric care in urban Haiti. Haiti is the poorest country in the Western Hemisphere, and a majority of its citizens live below the international poverty line[164]. Study participants described a range of strategies and techniques they used to "stay alive" and find appropriate care during and after pregnancy. Women in this study explained the effect of poverty on their lives, their pregnancies, their children, and their health care choices. Some of the interview subjects were destitute—living on the street, begging for food, or relying on the kindness of strangers to survive. Those who were better off were still struggling. Health care costs were a source of stress for women and their families.

Women were turned away from hospitals or referred to the MSF facility, because they were not able to pay for emergency services; the availability of free care was crucial for these women and their infants.

Data from both the survey and the interviews identify the many barriers these participants experienced in accessing emergency services. In addition to financial barriers, women were turned away from closed emergency obstetric hospitals, and admitted to and then discharged from other facilities frequently. Interview participants relied on word of mouth and referrals from friends and family when making their decision about where to seek care. Despite the fact that most participants had discussed their birth plan with a medical professional during antenatal care, participants described ad hoc decision-making about where to go to find emergency obstetrical care. These decisions about where to go were crucial in determining whether a woman received appropriate and timely care.

Problems with the health care system started during antenatal care for many participants. Survey and interview data indicated that some women received inadequate or inaccurate advice from their antenatal providers regarding their hypertension and preeclampsia. For example, several women reported being told to avoid salt in their diet, after being diagnosed with preeclampsia. Women with preeclampsia were, in many cases, unaware of danger signs of worsening preeclampsia, despite having adequate numbers of antenatal visits. Many participants reported that their antenatal providers did not adequately offer appropriate testing, referral or counseling when they were found to have high blood pressure. Many women presented to the MSF CRUO hospital with

severe preeclampsia, having attended antenatal care visits, but not having been appropriately referred for care for their preeclampsia.

Study Results in the context of the Three Delays Model

This study makes a vital contribution to the literature regarding the effects of the Three Delays.[67,71,74,75,81,82,86,88,90,92,93,99,103,140,151,153,157–160,162,165–173] Specifically, this study identifies first delays to leaving home as the major contributor towards long delays in preeclamptic women in Port au Prince, Haiti. It is the only study of delays to care among urban Haitian pregnant women.

A small number of studies[80,159] have examined the three delays for women living in urban areas, and particularly how first and second delays may be experienced in the urban context, or when a woman lives close to a facility. This research has found numerous factors that were associated with decreased access to care, including low educational attainment, difficulty finding transport, insecurity, financial constraints, and poor quality care at the facility. In the current study, long transportation delays were uncommon among both the preeclamptic and normal groups. However, difficulty in finding, arranging and paying for transport were key concerns identified in the qualitative interviews.

Prior studies of maternal mortality and the Three Delays model in a rural context have focused on the distance between women's homes and delivery facilities as a major factor in both first and second delays.[67,75,78,89,152,154,167,174] The first delay, the decision to leave home, has been shown to be longer for women living farther away from health

facilities. The second delay, the transportation delay, is necessarily longer for women living farther away from health centers. The current study, which found long delays among preeclamptic women living relatively close to the hospital, helps us understand how distance from the facility may impact women's decisions to leave home, and thus—somewhat counter-intuitively—add to the total time it takes to receive emergency care. Some studies have found that women's tendencies to leave home for facility birth are unaffected by distance when health facilities are less than five kilometers, or two kilometers away.[154,159] Despite living in an urban area, with relatively close access to several maternity hospitals, preeclamptic women in this study waited a median two hours to leave home to seek care, with about twenty percent (19.6%) of women waiting more than twelve hours. Moreover, analyses of delays in this study by neighborhood and region of Haiti found no relationship between distance and length of delay. Women living relatively close to the MSF facility had some of the longest delays to access care, even compared to women living outside of the Port au Prince area.

For women in this study, distance to the facility was clearly not the only relevant factor in deciding when to leave home and seek care. Some prior studies have also found that distance was not a predictor of delay.[150,154,168] In the Haitian urban context, distance to facility (measured here in time), is perhaps less salient of a factor than in rural settings.[175] Most women in this study live within two to five kilometers of a hospital; however, other factors inhibit access for many women.

The Three Delays model was developed to conceptualize the problem of accessing emergency obstetric care for women living far away from health centers.

Women in urban areas, like those living in Port au Prince, may live quite close to emergency obstetric facilities. As this study shows, however, access to emergency care is not straightforward, and many women nonetheless face delays to access care. What other factors may be relevant to urban women, and how could these be incorporated into the Three Delays Model? This study points to the importance of other factors, including the quality of antenatal care to identify, treat, refer and educate higher risk patients. Additionally, public safety concerns and traffic emerged as a concern among qualitative interview participants. As one of the few studies examining the utility of the Three Delays model in an urban context, this study calls into question the model's validity when applied in an urban context where women do not face long geographic distances to facilities, but who still encounter long delays. However, in the more than twenty years since this seminal study was published, it has guided very important work to reduce maternal and neonatal mortality. Updating this model to include urban women, and to focus less exclusively on distance to care and related transportation issues, can serve to include the experiences of these women who are also sometimes facing long delays to care.

More importantly than distance, women in this study were unclear about the danger signs of preeclampsia that might prompt the decision to leave. Only a minority of women were able to identify any danger sign, including headache or edema, which would indicate worsening preeclampsia. Other studies have found women's lack of knowledge of danger signs as a major contributor to delayed access to care.[71,102] Despite the fact that many preeclamptic women in this study were diagnosed with hypertension during

antenatal care, and that many of these women received the recommended number of antenatal visits, they were unaware of which symptoms should prompt immediate medical attention. Knowledge of preeclampsia danger signs was low, even among women who had been previously diagnosed with preeclampsia. Other studies of women in low-resource settings have also found low levels of knowledge of preeclampsia danger signs.[176,177] Knowledge of danger signs is an important component of women's readiness to deal with complications of pregnancy and childbirth.[178]

Women with preeclampsia in the current study were much more likely to have long delays at home after the onset of a problem compared to women without preeclampsia. Given that preeclampsia is extremely dangerous for mother and infant, ideally women would have the knowledge, sense of urgency and ability to seek care immediately when faced with any danger sign. However, we do not have data to compare rates of knowledge of danger signs between women with no antenatal care, and those with antenatal care. There may be positive effects of antenatal care on knowledge of danger signs, though the overall percentage remains low. The qualitative study findings also suggest that some antenatal care providers were providing incorrect and dangerous information to women diagnosed with preeclampsia, including advising them to avoid salt and stress as a method of managing their high blood pressure. There is limited published data about how frequently, and in what settings, antenatal providers themselves have incorrect information about preeclampsia, although it is clear from the research that does exist that Haiti is not the only example of poor quality antenatal care.[179,180]

In addition to poor quality antenatal care, women in this study also encountered difficulties in accessing high quality emergency care. The economic costs of seeking this care, including finding transport, calling on community and family networks for support, paying for services, and missing work are all prospective barriers.[81] There is extensive evidence from numerous settings that financial barriers are a major limit to women's access to emergency obstetrical care.[75,81,90,93,152,157,158,181] This study adds to the growing evidence that the costs of seeking care prevent many women who need emergency care from accessing it. Preeclamptic women in this study, most of whom described themselves as having limited financial means, described prohibitive costs of accessing emergency obstetrical care at the MSPP and private facilities where they sought care. Despite the fact that MSF offers free care, the hospital ideally functions as a referral facility; as such, MSF does not widely advertise their services to individuals. For the women who were interviewed, financial stresses were common, were a disincentive to leaving home to seek care, and increased the delays to receive emergency care.

It is also possible that women living in Port au Prince delayed leaving home due to concerns about safety. Several women in the qualitative interviews indicated that they waited until daylight to leave home for the hospital. One woman was stopped by the police from accessing care at the public hospital due to violence in the street, and was redirected to a private hospital where she was unable to pay for services. Public safety dangers may have forced women to wait at home longer. Studies from several countries indicated that private health care services were typically more expensive than public facilities.[182–184] Women may have also had to take more circuitous routes to the hospital

to avoid traffic. However, second delays were, on average, not lengthy for women in this study.

This study identifies potential areas for improvement in antenatal care practices. Survey data indicated that for women in this study, adequate antenatal care (four or more visits) was associated with lower risk of delay, but only among normal women. Women who had preeclampsia and also had four or more antenatal visits did not have shorter delays compared to those with less than four visits in this study. One of the main indications for antenatal care practices is to identify women with preeclampsia during the prenatal period, in order to act expeditiously to prevent morbidity and mortality for mother and baby, and to schedule additional visits in order to follow their illness more closely. Despite following WHO recommendations to attend four or more visits, sick women in this study were not able to avoid long, potentially dangerous delays to care, largely because many women had lengthy delays at home before leaving to seek care. According to mothers' responses, a subset of antenatal care providers provided inadequate education or the wrong information about the danger signs and risks of preeclampsia to women in this study. This lack of preeclampsia knowledge was widespread within the preeclamptic study population, with equal percentages of women with both very long (>24 hour) delays, and short (<6 hour) delays being able to report any preeclampsia danger sign. This lack of education and information was also evident in the survey, finding that forty percent of participants took at least one medication prescribed by their antenatal provider, but had no idea of the name of the medication or its function.

With apparently little attention paid to their hypertension by their medical providers, it would be extremely difficult for women themselves to understand its gravity. Additionally, many of these women delivered preterm as a result of preeclampsia; without a clear understanding of their disease and its treatment, they would have no way of knowing that they needed to access emergency obstetrical care months earlier than they were expecting, unless they were told so explicitly by their medical providers. For many of these women, an eclamptic seizure was the event that prompted leaving home for the hospital; the fact that most of these women had what would be seen as adequate antenatal care is a failure of this system to protect women from this life-threatening event.

Fifty-one participants had an eclamptic seizure, 16.4% of the preeclampsia study population (though twenty-two were excluded from the study because of incomplete data). Eclampsia is a rare complication of preeclampsia in the developed world. In one large study eclampsia occurred only three percent of the time among mothers with preeclampsia[185] with prevention of seizures through the use of magnesium sulfate and delivery of the baby in most cases. However, women must be appropriately diagnosed, treated and referred for care in order to prevent eclampsia. Despite the vast majority of study participants who attended four or more antenatal visits, prevention of eclamptic seizures did not occur. The fact that several women had an eclamptic seizure at home or en route to the hospital, speaks to a delayed decision to leave home to seek care—a long first delay.

Qualitative interview data highlighted and provided nuance to the indications

from survey data of participants receiving poor clinical care during their antenatal visits. On the survey questionnaire, many women reported discussing birth planning with their antenatal care provider. However, data from interviews shows that in deciding where to seek care, some women asked strangers along the route, made guesses based on experiences of friends, and tried multiple hospitals in order to receive the appropriate care. Additionally, interview data indicated that some providers seemed not to provide appropriate treatment, counseling, or follow-up for women diagnosed with preeclampsia or hypertension antenatally. Multiple respondents described being advised by their nurse or doctor to avoid salt or stress in order to manage hypertension that had been identified; neither of these courses of action would have any effect on preeclampsia, however. Unfortunately, advising a woman that she could control preeclampsia actively discourages her from seeking appropriate medical monitoring of this dangerous condition. By suggesting to women that their feelings or their nutrition were to blame for their hypertension, medical providers who provided inaccurate information shifted the burden of responsibility to the patients, rather than assuming the responsibility themselves to monitor and treat their condition.

With stress seen as the cause of high blood pressure by some patients, the obvious treatment from their perspective would be to reduce stress. What may be less obvious to these women, is that high blood pressure is a dangerous, potentially lethal diagnosis for them, and for their infant. Misunderstanding, or misinformation from their medical providers, could potentially cause delays in accessing emergency care for women with worsening hypertension.

The apparent lack of appropriate concern by medical providers about hypertension in pregnancy is directly reflected in the lack of concern that some participants described. However, this study cannot claim to understand the motivations or experiences of the medical providers treating these women. Knowing now that many of these participants experienced severe complications of pregnancy, including eclampsia and stillbirth, clearly indicates the need for intensive and evidence-based interventions for other women with preeclampsia. Further research needs to identify the perspectives and motivations of medical providers treating these patients. Some interview participants reported being suspicious of the motives of their medical providers, believing that they were trying to profit from ordering tests or cesarean sections, though it is not clear from interview data how exactly this would occur. This lack of trust could certainly compound the low efficacy of antenatal care for these participants.

Other survey findings also point to problems with participants' experiences with the Haitian health care system. Study participants who had previously had a health problem, or visited a doctor, had longer delays to access care than those who did not. Lengthened delay for these women could indicate that they received poor quality care, or were unsatisfied in some way, leading them to delay transfer to the hospital in this pregnancy. Previous research among pregnant women in Haiti found that perceived poor quality of medical services was associated with longer delays to access care.[74]

Survey data also provided insights into the nature of the third delay, which occurs at the hospital prior to the initiation of appropriate treatment. In this study, the time that women spent in the triage department prior to being admitted was used as a proxy

measure for this delay. Preeclamptic women in this study had a longer third delay (mean delay forty-eight minutes), despite the fact that they and their infants were more at risk than their normal counterparts (mean delay eleven minutes). Normal women admitted to CRUO were typically admitted because they were about to deliver. Their time spent in triage would therefore be expected to be expedited due to the medical necessity of moving the patient to the delivery room. However, very quick care is also absolutely essential for preeclamptic patients as well, just as for a woman imminently delivering. The total delay of forty-eight minutes for preeclamptic women appears relatively short given the acuity and population served by the MSF CRUO hospital. The system in place in the triage department of CRUO may have prioritized imminent delivery over a relatively stable preeclamptic patient. Both situations require urgent treatment; however, normal deliveries do not require as much decision-making or analysis by the triage staff as the decision to admit and treat for preeclampsia. Lab work, such as proteinuria exams, may have also delayed the admission of these preeclampsia patients. The sub-analysis of eclamptic patients also indicated that staff at MSF CRUO correctly prioritized eclamptic patients, who had a significantly shorter third delay (mean delay of 22 minutes), than preeclamptic patients (48 minutes).

Study Limitations

Study limitations include the self-reporting of delay, skewed data patterns impacting statistical analysis, and study design issues with the collection of neonatal outcomes.

The delays identified in the quantitative component of this study were self-reported by participants. As with all self-reported data, it is unclear to what extent study participants accurately reported delays. Although the interviewers attempted to identify and clarify the amount of time with the participants, it is certainly possible that the length of delays that were reported do not correspond to the true length of delays experienced by the participants. There was also a clustering of delays around twenty-four and forty-eight hours, indicating a tendency to report round figures among participants. It is possible that due to the inability of some eclamptic patients to report on first and second delays, and the need to exclude some of these participants because of this non-response, that the total delay for preeclampsia patients was inaccurately reported, and would likely be longer. In this case, this would increase the already significantly longer delay to access care that was identified by preeclamptic participants compared to normal participants.

The first delay presents particular challenges for measurement. The onset of the first delay corresponds to the onset of the emergency, which is subjective and specific to the experience of each participant. For women without preeclampsia, who were in labor, the onset of the first delay typically corresponded with the onset of strong contractions, or when their water broke. For women with preeclampsia, however, there was much more variation in how women understood the onset of the problem. For twenty-two participants, an eclamptic seizure or loss of consciousness marked the onset of the emergency. It is quite likely that these women who had an eclamptic seizure had other signs or symptoms of preeclampsia prior to the seizure that they were either unaware of, or did not consider to be an emergency. For those women who did not seek treatment for

symptoms occurring earlier, their reported delay to access care would appear to be artificially short. Data from the qualitative interviews reinforces the possibility that some preeclamptic women reported artificially short delays.

Ideally, all women in this study would have sought emergency obstetric care at the onset of any danger sign, such as headache, edema, or epigastric pain. However, in this sample, a minority of women were aware they were experiencing a danger sign, making it impossible to identify when they were truly at risk. Women's lack of knowledge of danger signs meant that they were unable to identify the start of the delay, leading to artificially shorter delays.

In addition to misjudging the timing of the first delay, participants may have also struggled to accurately identify the length of time for the second and third delays. More than three hundred participants rounded delays to one hour for transport, for instance. Without a second measure from which to triangulate the self-reported delays, it is difficult to know how accurately women reported these times. Self-report of delay is a limitation affecting many research studies that have attempted to measure the first and second delays.

Research personnel attempted to minimize these self-report limitations by carefully questioning women about the timing of the events leading to their admission to MSF CRUO. Research assistants led women through a verbal review of the events that had transpired, to attempt to help women identify and correctly establish the timing of each stage of the process. This process likely allowed some women to more accurately report and identify the events and delays that occurred prior to their admission.

However, reliable measurement of delays was difficult to achieve for women who had been unconscious or suffering eclamptic seizures upon arrival to the hospital. For the women who had suffered an eclamptic seizure, remembering and reporting delays were difficult, if not impossible. Eighty-two additional study subjects were added to account for higher than expected non-response rates among preeclamptic participants, including those who had eclamptic seizures. It is possible that preeclamptic women misreported delays, given the difficulty for them to remember accurately events leading up to their hospitalization. Additionally, twenty-two eclamptic women were excluded from the study because they were unable to answer study questions. More than half of the preeclamptic women who had eclamptic seizures were excluded from the analysis, because they could not report first or second delays, or because they were withdrawn from study participation due to their inability to answer study questions. These women, who suffered some of the worst effects, may be underrepresented in the data. Efforts were made by the research team to improve the reporting of delays for participants, by triangulating with family members who were present at the survey administration, but this was not always possible. Moreover, as described above, research assistants also attempted to help the participants themselves talk through the events that transpired prior to leaving home or during transport, while helping them to assign times to each event, in order to improve accuracy.

Another potential limitation of this study is that the shorter delays reported among the normal women may be partly due to the fact that they were, as a group, closer to delivery than their preeclamptic counterparts. While preeclamptic women had to

interpret the meaning of symptoms such as headache or visual disturbances, normal women had likely much less interpretation necessary, or possible. As labor progressed towards delivery, these normal participants would have no choice but to quickly move to the hospital if that was their intended place of birth. Without qualitative interview data on this group, it is difficult to understand how the first delays were experienced by the normal study participants.

Another limitation of this study is that it asked women to retrospectively report on prenatal events after she gave birth. The outcome of that birth, and the fact of having had complications, may bias participants' recollections of their experiences prior to delivery. Specifically for preeclamptic participants, who were universally being treated for a dangerous medical condition, this may have influenced their memory or reporting of the events that transpired during antenatal care, or their own actions in leaving home for the hospital. It is not clear from the data in which direction this could have biased the data. Did women potentially report shorter delays, knowing the gravity of the situation they faced once admitted? Or did women possibly lengthen delays to include symptoms that had previously gone unnoticed? Further research would be needed to elucidate the potential self-report issues in first delay for this population.

Prior studies have identified demographic risk factors, such as age, education, or economic status, as predictors of delayed access to care.[67] Those demographic factors were not found to affect the length of delay in this study. Some factors that might be expected to confer some benefit, such as secondary school education or good economic status, were not found to affect the length of delay for women in this study. Women who

experienced other factors that could be expected to lengthen delay, such as being an internally displaced person (IDP), also did not have longer delays to care.

However, statistical power may have been insufficient to see differences in these areas. There was a trend towards shorter delay among preeclamptic women with "doing well" or "good" economic status (4.9 hours versus 15.2 hours), though this did not reach the level of statistical significance, probably given the small number of women in this group (n=25) faring well economically. This trend was reversed among the normal group, with longer delays among the women with good economic status (12.1 hours versus 6.6 hours, n=12), although the differences were also not statistically significant. It is difficult to understand how better economic status could lead to longer delays, as studies in many settings have found the opposite to be true.

This study aimed to identify the role of delayed access to care in poor clinical outcomes for mothers or babies. However, the association between long delays to care and poor clinical outcomes was not clearly evident from the data. Several factors have affected the lack of association in this study. Difficulties in assessing delay may have led to an under-reporting of delay for preeclamptic women. The study sample size may have been insufficient to find real associations that do exist. Additionally, the generally low economic status and difficulty to find health care for all participants may have minimized differences between the delayed and not delayed groups. Finally, neonatal death was not able to be accurately identified in this study, due to the inability to track neonatal outcomes after the time of survey administration. However, it is likely that neonatal deaths, even if accurately reported, would have been too rare to have seen major

differences among the groups.

Inability to accurately document neonatal outcomes was a limitation of this study. The study was designed to be anonymous. Therefore, there was no way to track neonatal outcomes after the survey questionnaire was completed, which was oftentimes on the first postpartum day. Birth outcomes were recorded (APGAR score, admission to NICU), as well as any other outcomes (neonatal death) up to the time of administration of the questionnaire. Many infants born to preeclamptic mothers were either born preterm, were low birth weight, or both. These babies would have a higher risk for neonatal death, which could have occurred after their first day of life, when the outcome was recorded. Some of these babies may have initially responded to resuscitative measures and had a good APGAR score. However, problems with respirations, infections or other newborn problems that are initially managed at birth can cause increasing problems after the first day of life.[186]

Without being able to identify which babies survived, and which did not, it is impossible to measure the full effect of delayed access to care on this outcome. A different study design would need to be used to track the outcomes of babies over the course of their hospitalization to ensure an accurate reporting of neonatal death. However, this outcome may not have been different even if neonatal deaths were accurately recorded. Haiti reports a neonatal mortality rate of 27/1,000 live births.[1] Even if there were twice as many neonatal deaths for women in the preeclampsia subgroup, there would still not be enough power to observe differences among women with long delays. More common outcomes, where differences should be more likely, such as low

APGAR score, were not significantly different for infants of mothers with long delays.

Another study limitation is the possibility that some women who were truly preeclamptic were misclassified as normal, and that other women who were not preeclamptic but merely had hypertension, were classified as preeclamptic. Fifteen participants in the normal group stated that they had been diagnosed with preeclampsia during that pregnancy, and some of them had elevated blood pressure readings on admission to MSF. If these women were on the verge of delivering their infant, it is possible that staff did not have the time to distinguish between blood pressures that can be normally elevated during delivery, and those indicating preeclampsia. Misclassification of women by preeclampsia diagnosis could have biased the delays reported by these groups, by artificially lengthening delays in the normal group.

Many of the study participants had no history of medical care prior to their pregnancy. Another limitation of this study was the possibility that women who had chronic hypertension were misdiagnosed as preeclamptic, because they only sought medical care during their pregnancy. When hypertension is identified during antenatal care, it is difficult to differentiate between hypertension caused by pregnancy, and hypertension that is preexisting pregnancy. MSF CRUO attempted to accurately diagnose cases of preeclampsia by testing for proteinuria, which is specific for preeclampsia. However, it may be true that some women who received preeclampsia diagnoses during antepartum visits were misdiagnosed.

Finally, ten percent of normal women in this study also reported a previous history of preeclampsia, roughly double the expected percentage of preeclampsia in most

settings, according to published estimates[49]. Several possibilities could explain this relatively high rate of preeclampsia history among the normal subgroup. Haiti has a very high prevalence of hypertension, which may contribute to higher than expected cases of preeclampsia. For the women in this study, they may have truly had preeclampsia, but were fortunate to not develop it in this pregnancy. They may also have been misdiagnosed in this pregnancy and their preeclampsia may have been missed. Regardless of personal history, testing for preeclampsia at antenatal care should be standard for all women. Additionally, these women may have misunderstood the question and answered affirmatively in error. Self-reported preeclampsia histories may be subject to some error due to self-reporting[187], as is seen in this finding.

Summary

This study adds to the knowledge about how the Three Delays model is relevant to pregnant women living in urban areas. Despite having much shorter distances to travel, preeclamptic women in this study had long average delays to access emergency obstetric care. These delays would be expected to have negative consequences for both maternal and neonatal morbidity and mortality. However, in this study, longer delays were not associated with poorer clinical outcomes for mother or baby when compared to a sample of mothers without preeclampsia. This finding could be the result of inaccurate self-report of delay, or a study design that did not accurately capture longer-term neonatal outcomes. Overall high levels of poverty, low access to health care, and poor health status among both groups could have minimized differences between the preeclamptic

and normal groups, masking the effects of delays.

What is clear from both survey and interview data is that antenatal care, which was widely attended by participants in this study, was of limited usefulness to this study population. Despite their reported assiduous attendance, preeclamptic participants were unable to identify danger signs of preeclampsia, and had long delays at home before seeking care for danger signs. Women who had shorter (<6 hour) or longer (>24 hour) delays had equivalent attendance at antenatal care visits, and were equally unlikely to remember any preeclampsia danger signs. Many antenatal care providers did not appropriately manage hypertension in these patients, leading to dangerous situations for these mothers and babies. This study highlights the urgent need for training of antenatal care providers on correct methods to screen, treat, refer and educate patients with preeclampsia.

CHAPTER 8: CONCLUSIONS AND RECOMMENDATIONS

Summary

This paper has presented the findings of a mixed methods study of delayed access to emergency obstetrical care for preeclamptic women in Port au Prince, Haiti. This study found long delays to accessing care for these sick women. Long delays were primarily the result of the first delay, when some women stayed at home for many hours prior to seeking care. This study did not identify demographic risk factors associated with delayed access to care. Women's health prior to pregnancy apparently did not affect their delays to accessing care, with the exception of preeclamptic women who had previously had a health problem; these women did experience significantly longer delays. Adequate antenatal visits during pregnancy were not associated with shorter delays for preeclamptic women. First delays longer than six hours for preeclamptic and normal women were not associated with poorer clinical outcomes, although neonatal death was not included in the analysis.

Interviews with women and family members of women affected by preeclampsia highlighted the effects of poverty on these women's lives, and on their ability to access timely emergency care when they became ill. Financial barriers to care affected where and how women with preeclampsia were able to access emergency care. Overwhelming poverty added stress to the lives of women already dealing with substantial medical issues.

Despite the fact that most participants had accessed antenatal care, this was not associated with shorter delays to care, increased knowledge of preeclampsia, or better

referral or treatment of this dangerous syndrome before delivery. Lack of knowledge of preeclampsia, its danger signs, and its devastating consequences led many women to stay at home for many hours after the onset of worsening symptoms and before seeking care. Many of these participants reflected on the importance of having high quality, accessible, free care for obstetric emergencies, such as the care provided by the MSF hospital in Port au Prince.

Conclusions

Pregnant women in Port au Prince who develop preeclampsia must navigate a complex, difficult to understand, and prohibitively expensive system of health care to receive appropriate, high quality emergency obstetric care. While this study was not designed to study the impacts of antenatal care on delayed access to intrapartum care, our findings suggest lost opportunities for patient education, birth planning, prevention of preeclampsia in high risk women, appropriate testing and treatment of hypertension, and appropriate referral of high risk cases. Women with preeclampsia in this study often delayed leaving home for the hospital for many hours after the onset of their symptoms; even after leaving, many had to visit several hospitals before being admitted and appropriately treated.

High quality, free obstetric care, such as that being offered by MSF, is essential to treat the life-threatening complications of preeclampsia and eclampsia and to prevent maternal and perinatal mortality. With the end of the "Maman Ak Timoun An Sante" (Healthy Mothers and Babies) program in 2013, access to obstetric care has become much more difficult for many women in Port au Prince, as funding for staff and supplies

dried up, and patients were forced to pay large sums of money for care. MSF CRUO hospital fills a vital role in this situation, by continuing to offer high quality, free care to sick pregnant women. Because the MSF CRUO hospital is meant to serve as a referral facility, and not as a duplicate or parallel system to the MSPP, its services and criteria for admission are not widely advertised to the public at large. However, given the breakdown of the public hospital system, women may not be able to access other facilities that could initiate treatment, and then refer them to MSF.

Recommendations for future research

Very few published studies have examined the unique health problems of Haitian pregnant women, including the prevalence of preeclampsia among this population. Small studies suggest a high prevalence of preeclampsia[188], which may be linked to documented high rates of hypertension in the general Haitian population[108,146]. As one of the major causes of maternal mortality worldwide, and likely in Haiti, preeclampsia should be studied to identify incidence and prevalence, in order to accurately assign resources to aiding women with this problem.

The scope of the problem of preeclampsia in Haiti is unknown; prevalence studies can help public health researchers, MSPP staff, and clinicians to assign appropriate resources and time to address it, as needed. *The first recommendation is that further research should examine the prevalence of hypertension and preeclampsia among women seeking antenatal care services, as well as the types of services and care that are provided to them.* The costs of this treatment, and its efficacy based on international norms, should also be investigated. Research should also identify the specificity of

preeclampsia in the Haitian setting: a screening of women in antenatal care, along with a survey of women with preeclampsia should examine the prevalence of chronic hypertension, preeclampsia, eclampsia, preterm birth, and maternal and neonatal morbidities and mortality in order to inform a public health strategy to combat this syndrome.

This study also identified potential problems with the provision of antenatal care services in Port au Prince. Although most women attended the recommended number of visits, the content of these visits was apparently not sufficient to appropriately manage these women's preeclampsia, as evidenced by low comprehension of preeclampsia danger signs, long first delays at home once symptoms arose, and limited occurrences of timely referral from outpatient settings. Merely meeting the four visit threshold is not adequate to effectively diagnose and treat preeclampsia patients, according to mothers' responses. Preeclampsia patients, who are by definition high risk, need at a minimum closer monitoring, more antenatal visits, and careful planning for the time and place of delivery to ensure prevention of morbidities and mortality. *A second recommendation is that further studies examine the content of these antenatal visits and provide targeted recommendations essential to devising a plan for improving the quality of these prevention services*.

A third recommendation is for researchers to undertake a prospective study of pregnant women in Port au Prince, to monitor the quantity and quality, as well as the costs, of the antenatal care they receive, and the resulting outcomes of their pregnancies. A mixed method design, which incorporated interviews with antenatal providers, could

add to the understanding about the experience and understanding of providers who are treating women with preeclampsia. Understanding where women seek care, the providers they see, the content of visits, the financial costs of care, and mechanisms currently in place to treat sick women would be the next step to address some of the issues identified in this study. There are several large obstetric hospitals in Port au Prince; surveys of women admitted to these hospitals could identify the names and locations of antenatal care providers, including public and private facilities, hospital or clinic based services, who could then, in turn, be mapped and surveyed themselves. What training do these providers have? What supplies and medications are available for the diagnosis and treatment of preeclampsia? What is the content of patient education regarding hypertension and preeclampsia? What happens when a woman is found to have hypertension or preeclampsia? Interviews with antenatal care providers, to understand their perspective, would represent an essential component to have a more comprehensive picture of the issues at play.

Our study found that women still endured long delays to access emergency obstetrical care, even in an urban setting, and despite living relatively close to hospitals. This study calls into question the appropriateness of the Three Delays model for urban settings. Most of the Three Delays research has focused on women in rural areas, and has examined how the distance to facilities has affected delays to care. With increasing urbanization in contexts around the globe, researchers need to focus attention on understanding the specific barriers and delays faced by women in these growing cities. *As a fourth recommendation, researchers should examine how the specific context and*

challenges of urban living can impact access to emergency obstetrical care by researching the delays, and causes of delays, for pregnant women. An expanded Three Delays model that includes experiences of urban women, or a new model of delays to care, needs to incorporate the experiences and difficulties faced by these women who may live close to a facility, but still struggle to receive appropriate medical care for obstetric emergencies. Qualitative data in this study indicate that transport options, traffic, public safety issues, and the organization of public health hospitals all have the potential to delay women's access to emergency obstetrical care.

MSF CRUO provides care to hundreds of sick women every month who have few other options for life saving care. As part of their mission in Haiti, and *as a fifth recommendation, MSF should consider funding a prospective study to follow outcomes of women admitted with preeclampsia and eclampsia.* While this study has established the difficulties faced by many women prior to admission, little is known about the morbidities faced by women after delivery. Specifically, the prevalence of chronic hypertension among this population is not known, as well as their continued need for treatment and follow up. Knowledge of maternal morbidities following delivery can help orient the MSF program towards appropriate care for this population, as well as to inform MSPP efforts for this vulnerable population.

Recommendations for MSF CRUO program

MSF CRUO created and funded a position of maternity surveillance officer in 2014. This post was formed to create linkages among obstetric facilities, in order to gather information about maternity care issues in Port au Prince, and also to share

information about the MSF CRUO hospital with referring facilities and providers. Because CRUO is designed to operate as a referral facility, ideally admitting most patients from other maternity centers not able to handle their cases, creating linkages and networks with obstetric providers is key. The initial goals for the position included the creation of forums for discussion amongst MSPP staff, sharing of information about ambulance services, and providing information about CRUO admission criteria and services to staff from public obstetric hospitals. The maternity surveillance officer, if staffed by a qualified and trained person, can be key in addressing some of the recommendations generated from this study.

The maternity surveillance officer can work to identify the main sources of antenatal care for women admitted to CRUO, so as to enable more direct referrals from outpatient care facilities. Primary health care services, like emergency services, are poorly organized and not transparent in Port au Prince; it is not clear where the majority of women are seeking services. Some women may receive antenatal services from the outpatient department of local MSPP hospitals, some from NGO services or missionary clinics, and others from private services. After surveying women in CRUO, the surveillance officer can create a map of antenatal care providers. Once this mapping exercise is complete, MSF staff can work to create linkages with these antenatal care providers, enabling more effective and direct referrals to the CRUO hospital, ensuring timely treatment for women diagnosed with preeclampsia. Ultimately, more systematic referrals from antenatal providers to MSF CRUO hospital could bypass some of the problems that were identified by interview participants about referrals from local

hospitals. Mapping of antenatal care access of MSF patients could also augment similar activities done for research purposes, to further understanding of how women access antenatal care.

A conference on maternity care in Port au Prince, organized by MSF in Spring 2014 represents one notable success of the maternity surveillance and advocacy program. This conference brought together many players from the MSPP, NGO partners, and the national ambulance service to discuss emergency obstetrical care. In this same mode, MSF should consider convening a conference targeting antenatal care providers. This conference could include components of medical education for providers, focusing on preeclampsia in the antenatal period in the Haitian context, as well as opportunities to share information and encourage earlier and more timely referrals for preeclamptic patients. This conference could also highlight for the public and the press the importance of improving antenatal care quality, which could then in turn ensure that the Ministry continues to focus attention on this subject.

As MSF has done continually in Haiti, it should continue to advocate strongly for free emergency obstetric care for Haitian women. The end of the Maman Ak Timoun An Sante program has left Haitian women struggling to pay user fees for services. Particularly problematic is the fact that cesarean section, a necessary and important life-saving component of emergency obstetric services, is typically beyond the financial reach of most Haitian families. Free, high quality services, like those offered by MSF, are essential to saving the lives of mothers affected by preeclampsia and their babies, as well as other obstetric emergencies. MSF should continue to advocate with the government of

Haiti to fund public hospitals appropriately. Additionally, MSF should also advocate for stronger medical education and supportive supervision for antenatal care providers. With the demise of the countrywide free obstetric program, the MSF program is providing high quality, financially accessible emergency obstetrical care, which is not found at any other hospital in Port au Prince today.

CRUO care is predicated upon the hospital being a referral facility. However, the referral network upon which CRUO relies is barely functional. Multiple interview respondents indicated that it is difficult or impossible to find any care outside of MSF CRUO. Other women reported that they were referred to MSF only after spending large amounts of money at a referring facility, further limiting access. Although women can also self-identify and present individually for care, the model of CRUO is built on the assumption that most patients will be referred from facilities not equipped or staffed to handle acute emergencies. *This study calls that model into question*. Given our findings that women have difficulty accessing and paying for care at public hospitals, MSF should continue to use a broad-based advocacy strategy, including direct talks with the MSPP, news articles, patient testimonies, and internal publications to push the Haitian government and donors to fund emergency obstetric programs fully, and to monitor them for quality. In the absence of free governmental obstetric care programs, however, and given the eventual end of its presence, MSF will need to develop a unique strategy for devolving emergency obstetrical care programs back under government control. MSF has to continually choose between continuing long-running programs that are successful in savings lives, versus opening new projects in the myriad of emergency contexts around

the world. As with all MSF programs, the continued existence of the CRUO program depends on a complex analysis of the state of "emergency" in that context, and the program's effects on mortality reduction. MSF's current five-year plan to continue this program will come under review in 2019.

MSF runs hospitals with maternity programs in many urban areas throughout the world. The results of this study can help MSF reflect on the need for these hospitals' presence, oftentimes in the vicinity of Ministry of Health hospitals. As MSF makes decisions about where to open and where to continue obstetric programs, the results of this study can provide evidence about the importance of free, high-quality emergency care for women with obstetric complications. Other MSF programs can also use these findings to ensure that the quality care they offer is timely, and that women do not face long delays to reach it, in part by not assuming that geographic presence and proximity equals timely access. As has been found in other contexts, the presence of health facilities is not enough to ensure that women will have access to their services.[161]

A further recommendation for the MSF CRUO staff comes from the analysis of the third delay. The results of the quantitative data analysis found that preeclamptic women have a statistically longer wait in the triage department of CRUO than their normal counterparts. Some of this difference is likely due to the nature of the normal women's admission criteria; for most: imminent delivery. However, even eclamptic women in this study had a longer wait than women imminently delivering. Eclamptic patients require emergent supportive care to lower the risk of maternal and perinatal mortality, and to minimize resulting morbidities. CRUO staff should consider reviewing

the protocols for staff in triage, and how they prioritize their workload and patients in order to reduce these waiting times for very sick patients.

With almost a third of admissions due to preeclampsia and eclampsia, and based on the limited studies showing a very high prevalence of this syndrome in Haiti, CRUO should target staff education and training on prevention and treatment. These study results can help focus attention on the specific care needed for these vulnerable women and infants, and ensure that the quality of care being offered is consistently high. The data about third delay for preeclamptic patients can inform training for triage staff, for instance. MSF should also work to improve the continuity of care for women discharged from CRUO, to ensure they have the minimum of information about their condition, and their risks in future pregnancies. Referral for continued treatment of essential hypertension is likely difficult due to health system constraints, but crucial for these women's long-term health.

Finally, this study showed that for many women, decisions about when, how, and where to seek care are based on a poor understanding of the signs and dangers of preeclampsia. Public health campaigns targeting pregnant women themselves could circumvent some of the problems associated with poor quality antenatal care, by giving women the tools to make better decisions about when to seek emergency care, and hopefully lessen delays to care. Of course, in order to make public health campaigns effective, women need high quality, accessible options for receiving care, both before and during birth.

Recommendations for other settings

The results of this study may also help focus attention on the problems facing sick pregnant women in other urban, low-income settings around the world. While researchers and public health officials have worried, with good reason, about reaching women who live far from facilities, and who must travel great distances to reach services, this study, as well as other literature,[189] also indicates a vital need for attention to urban women, particularly given the rapid urbanization of developing countries. Some research has found higher levels of health risks such as obesity, exposure to pollutants, and effects from natural disasters among urban residents.[18] Specific health risks among urban pregnant women are largely unknown; our results indicate that proximity to health care is not enough to ensure access to care. This study adds to the public health literature calling for attention to the specific issues facing urban women, finding that despite geographic proximity to services, urban pregnant women are suffering from preventable morbidities and mortality.

The problems that women in this study overcame to find care, such as traffic or gang violence, are not unique to Haiti. The manifestation of how delays to care affected Haitian women are specific to this context; the sites and relative importance of how these and other issues play out in Port au Prince make inquiry into these and other issues critical. How do these same issues impact obstetric care, and what is their specific contextual expression in Lagos, or Managua, or any other growing metropolis in a poor country around the world? Research into delayed access to care is important for urban women, as well as rural women. With increasing population movements, and explosive

urbanization in many parts of the world, this issue will only grow in importance in the coming years.

The Three Delays model has been instrumental in drawing attention to the obstacles faced by many women in accessing emergency obstetrical care. This study draws attention to the applicability of this model for urban settings, and highlights the need to include urban women's experiences and barriers. Understanding and conceptualizing how women as sick as those identified in this study, who live within walking distance to a hospital, and who still have long delays, is crucial to finding solutions.

Summation

Pregnant women with preeclampsia in Port au Prince, Haiti overcome poverty, ineffective antenatal care, poorly organized health care systems, and even overwhelming traffic to access emergency obstetrical care. The MSF CRUO hospital offers free, high quality emergency care to these women and their infants. The resilience and grit of these Haitian women is impressive, and it should be matched by perseverance and determination on the part of the medical system to address the myriad needs of these vulnerable patients. Haitian government officials must work to improve medical education and supervision for antenatal care providers and emergency obstetric providers, as well as to improve the accessibility and affordability of public hospitals in Port au Prince. Researchers should continue to work to illuminate the scope and nature of the problem of preeclampsia for Haitian women.

Annex 1: Consent form - Survey

Background

The researchers, with the permission of Médecins Sans Frontières (MSF), the Ministry of Health (MSPP), and the Haitian National Bioethics Committee, would like to ask you some questions from a survey. About 400 women who delivered a baby at this hospital will be asked to participate in the research study. Your care will not be affected by your decision to take part in the study or not.
The study will take place in a private place here in the hospital. The study involves an interview where we ask you about 40 questions. It will take about 30 minutes.
The study will also use information routinely gathered from you and your baby's hospital chart.

Purpose

Pregnant women and newborn babies have a bigger risk of dying in Haiti than in many countries around the world. Problems that can happen during pregnancy or delivery can cause illness or death for a woman or baby.
At this time, we don't know why some women in Haiti have problems during their pregnancy or birth. We think there may be some factors that happen during the pregnancy that can affect whether or not she or her baby develops a problem. We think women who have less education, less financial support, or use a traditional midwife might have more problems. We would like to ask you about your life before you arrived here to the hospital. Your answers can help us to understand which factors might lead to problems for women or babies. The information we gather may help improve care in the future for pregnant women in Haiti.

What Happens In This Research Study

You will be one of approximately 400 subjects to be asked to complete a survey as part of the research study.

The research will take place here at The Emergency Obstetric Referral Hospital (CRUO), the hospital where your baby was born.

The study will take place in a private place here in the CRUO hospital. The study involves an interview where we ask you about 40 questions. It will take about 30 minutes. We will ask you questions about your life, your health, your pregnancy, and what you did before you came to the hospital.
The study will also use information routinely gathered during for you and your baby's hospital chart. The researcher will record some information, including yours and your baby's medical diagnoses, from your medical chart after the interview.

Risks and Discomforts

There are very few risks to participating in this study. It may be upsetting to talk about your pregnancy or delivery if you or your baby had a problem. We can refer you to a mental health counsellor if you feel upset during the survey. You can also decide not to participate, or to stop your participation, if you think you will feel upset. The time to participate may be an inconvenience.

There is a small risk that confidential but anonymous information that you tell us could be mistakenly shared with someone outside the research team. We will minimize this risk by not writing down your name or address on any forms.

There may be unknown risks/discomforts involved. Study staff will update you in a timely way on any new information that may affect your health, welfare, or decision to stay in this study.

Potential Benefits

You will receive no direct benefit from your participation in this study. However, your participation may help the investigators better understand why some women have problems during their labor or delivery.

Alternatives

Your alternative is to not participate in the study.

Subject Costs and Payments

There are no costs to you for participating in this research study. You will not be paid to participate in this research study.

Confidentiality

Personal information will be kept confidential and will not be shared with anyone outside the study. We will not write your name or address down, and we will not be able to identify you from the answers you give us. Only people working on the study will be able to view your information. All of your answers, and this form, will be kept in a locked file here at the hospital, and then destroyed 3 years after the end of the research. Information from this study and from your medical record may be used for research purposes and may be published; however, your name will not be used in any publications.

Subject's Rights

By consenting to participate in this study you do not waive any of your legal rights.

Giving consent means that you have heard or read the information about this study and that you agree to participate. You will be given a copy of this form to keep.

If at any time you withdraw from this study you will not suffer any penalty or lose any benefits to which you are entitled.

You may obtain further information about your rights as a research subject by calling the Office of the Institutional Review Board of Boston University Medical Center at 001-617-638-7207. You can also contact the Haitian Ethical Review Board at +509 3701 5166, or the office of Médecins Sans Frontières at +509 2811 0110.

The investigator or a member of the research team will try to answer all of your questions. If you have questions or concerns at any time, or if you need to report an injury while participating in this research, contact Katharine Hutchinson, BA, MSN, CNM, at +509 4892 7531 during the day or after hours.

Right to Refuse or Withdraw

Taking part in this study is voluntary. You have the right to refuse to take part in this study for any reason. If you decide to be in the study and then change your mind, you can withdraw from the research at any time, and for any reason. Your participation is completely up to you. Your decision will not affect your being able to get health care at this institution or payment for your health care.

If you choose to take part, you have the right to stop at any time. If there are any new findings during the study that may affect whether you want to continue to take part, you will be told about them as soon as possible.

The investigator may decide to discontinue your participation without your permission because he/she may decide that staying in the study will be bad for you, or the sponsor may stop the study.

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

Subject (Signature and Printed Name) Date

Person Obtaining Consent (Signature and Printed Name) Date

(In case of illiterate subjects)
Witness (Signature and Printed Name) Date

Annex 2: Consent Form - In-depth Interview

Background

The researchers, with the permission of Médecins Sans Frontières (MSF), the Ministry of Health (MSPP), and the Haitian National Bioethics Committee, would like to ask you some questions. About 30 women who delivered a baby at this hospital will be asked participate in the research study. Your care will not be affected by your decision to take part in the study or not.
The study will take place in a private place here in the hospital. The study involves an interview where we ask you questions about yourself and your life. It will take about 60 minutes.

Purpose

Pregnant women and newborn babies have a bigger risk of dying in Haiti than in many countries around the world. Problems that can happen during pregnancy or delivery can cause illness or death for a woman or baby.
At this time, we don't know why some women in Haiti have problems during their pregnancy or birth. We think there may be some factors that happen during the pregnancy that can affect whether or not she or her baby develops a problem. We think women who have less education, less financial support, or use a traditional midwife might have more problems. We would like to ask you about your life before you arrived here to the hospital. Your answers can help us to understand which factors might lead to problems for women or babies. The information we gather may help improve care in the future for pregnant women in Haiti.

What Happens In This Research Study

You will be one of about 30 women to be asked to complete an interview as part of this research study.

The research will take place here at The Emergency Obstetric Referral Hospital (CRUO), the hospital where your baby was born.

The study will take place in a private place here in the CRUO hospital. The study involves an interview where we ask you questions about yourself and your life. It will take about 60 minutes. We will ask you about what you did before you came to the hospital, how you made the decision to come, what barriers you may have faced, and who helped you.

Risks and Discomforts

There are very few risks to participating in this study. It may be upsetting to talk about your pregnancy or delivery if you or your baby had a problem. We can refer you to a mental health counsellor if you feel upset during the survey. You can also decide not to participate, or to stop your participation, if you think you will feel upset. The time to participate may be an inconvenience.

There is a small risk that confidential but anonymous information that you tell us could be mistakenly shared with someone outside the research team. We will minimize this risk by not writing down your name or address on any forms.

There may be unknown risks/discomforts involved. Study staff will update you in a timely way on any new information that may affect your health, welfare, or decision to stay in this study.

Potential Benefits

You will receive no direct benefit from your participation in this study. However, your participation may help the investigators better understand why some women have problems during their labor or delivery.

Alternatives

Your alternative is to not participate in the study.

Subject Costs and Payments

There are no costs to you for participating in this research study. You will not be paid to participate in this research study.

Confidentiality

Personal information will be kept confidential and will not be shared with anyone outside the study. We will not write your name or address down, and we will not be able to identify you from the answers you give us. Only people working on the study will be able to view your information. All of your answers, and this form, will be kept in a locked file here at the hospital, and then destroyed 3 years after the end of the research. Information from this study and from your medical record may be used for research purposes and may be published; however, your name will not be used in any publications.

Subject's Rights

By consenting to participate in this study you do not waive any of your legal rights.

Giving consent means that you have heard or read the information about this study and that you agree to participate. You will be given a copy of this form to keep.

If at any time you withdraw from this study you will not suffer any penalty or lose any benefits to which you are entitled.

You may obtain further information about your rights as a research subject by calling the Office of the Institutional Review Board of Boston University Medical Center at 001-617-638-7207. You can also contact the Haitian Ethical Review Board at +509 3701 5166, or the office of Médecins Sans Frontières at +509 2811 0110.

The investigator or a member of the research team will try to answer all of your questions. If you have questions or concerns at any time, or if you need to report an injury while participating in this research, contact Katharine Hutchinson, BA, MSN, CNM, at +509 4892 7531 during the day or after hours.

Right to Refuse or Withdraw

Taking part in this study is voluntary. You have the right to refuse to take part in this study at any time. If you decide to be in the study and then change your mind, you can withdraw from the research for any reason, at any time. Your participation is completely up to you. Your decision will not affect your being able to get health care at this institution or payment for your health care.

If you choose to take part, you have the right to stop at any time. If there are any new findings during the study that may affect whether you want to continue to take part, you will be told about them as soon as possible.

The investigator may decide to discontinue your participation without your permission because he/she may decide that staying in the study will be bad for you, or the sponsor may stop the study.

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

Subject (Signature and Printed Name) Date

Person Obtaining Consent (Signature and Printed Name) Date

(In case of illiterate subjects)
Witness (Signature and Printed Name) Date

Annex 3: Consent - Survey, Legally Authorized Representatives

Background

The researchers, with the permission of Médecins Sans Frontières (MSF), the Ministry of Health (MSPP), and the Haitian National Bioethics Committee, would like to ask you some questions about your relative from a survey. About 400 women or their legal representatives who delivered a baby at this hospital will be asked to participate in the research study. The health care of your relative will not be affected by your decision to take part in the study or not.
The study will take place in a private place here in the hospital. The study involves an interview where we ask you about 40 questions. It will take about 30 minutes.
The study will also use information routinely gathered from your relative and her baby's hospital chart.

Purpose

Pregnant women and newborn babies have a bigger risk of dying in Haiti than in many countries around the world. Problems that can happen during pregnancy or delivery can cause illness or death for a woman or baby.
At this time, we don't know why some women in Haiti have problems during their pregnancy or birth. We think there may be some factors that happen during the pregnancy that can affect whether or not she or her baby develops a problem. We think women who have less education, less financial support, or use a traditional midwife might have more problems. We would like to ask you about your relative's life before she arrived here to the hospital. Your answers can help us to understand which factors might lead to problems for women or babies. The information we gather may help improve care in the future for pregnant women in Haiti.

What Happens In This Research Study

You will be one of approximately 400 subjects to be asked to complete a survey as part of the research study.

The research will take place here at The Emergency Obstetric Referral Hospital (CRUO), the hospital where your baby was born.

The study will take place in a private place here in the CRUO hospital. The study involves an interview where we ask you about 40 questions. It will take about 30 minutes. We will ask you questions about your relative's life, her health, her pregnancy, and what she did before she came to the hospital.
The study will also use information routinely gathered from your relative and her baby's hospital chart. The researcher will record some information, including her and her baby's

medical diagnoses, from the medical chart after the interview.

Risks and Discomforts

There are very few risks to participating in this study. It may be upsetting to talk about your relative's pregnancy or delivery if she or her baby had a problem. We can refer you to a mental health counsellor if you feel upset during the survey. You can also decide not to participate, or to stop your participation, if you think you will feel upset. The time to participate may be an inconvenience.

There is a small risk that confidential but anonymous information that you tell us could be mistakenly shared with someone outside the research team. We will minimize this risk by not writing down your or your relative's name or address on any forms.

There may be unknown risks/discomforts involved. Study staff will update you in a timely way on any new information that may affect your relative's health, welfare, or decision to stay in this study.

Potential Benefits

Neither you nor your relative will receive direct benefit from your participation in this study. However, your participation may help the investigators better understand why some women have problems during their labor or delivery.

Alternatives

Your alternative is to not participate in the study.

Subject Costs and Payments

There are no costs to you for participating in this research study. You will not be paid to participate in this research study.

Confidentiality

Personal information will be kept confidential and will not be shared with anyone outside the study. We will not write yours or your relative's name or address down, and we will not be able to identify you or your relative from the answers you give us. Only people working on the study will be able to view your information. All of your answers, and this form, will be kept in a locked file here at the hospital, and then destroyed 3 years after the end of the research.
Information from this study and from your medical record may be used for research purposes and may be published; however, yours or your relative's name will not be used in any publications.

Subject's Rights

By consenting to participate in this study you do not waive any of your legal rights. Giving consent means that you have heard or read the information about this study and that you agree to participate. You will be given a copy of this form to keep.

If at any time you withdraw from this study you will not suffer any penalty or lose any benefits to which you or your relative are entitled.

You may obtain further information about your rights as a research subject by calling the Office of the Institutional Review Board of Boston University Medical Center at 001-617-638-7207. You can also contact the Haitian Ethical Review Board at +509 3701 5166, or the office of Médecins Sans Frontières at +509 2811 0110.

The investigator or a member of the research team will try to answer all of your questions. If you have questions or concerns at any time, or if you need to report an injury while participating in this research, contact Katharine Hutchinson, BA, MSN, CNM, at +509 4892 7531 during the day or after hours.

Right to Refuse or Withdraw

Taking part in this study is voluntary. You have the right to refuse to take part in this study for any reason. If you decide to be in the study and then change your mind, you can withdraw from the research at any time, and for any reason. Your participation is completely up to you. Your decision will not affect your relative being able to get health care at this institution or payment for your health care.

If you choose to take part, you have the right to stop at any time. If there are any new findings during the study that may affect whether you want to continue to take part, you will be told about them as soon as possible.

The investigator may decide to discontinue your participation without your permission because he/she may decide that staying in the study will be bad for you, or the sponsor may stop the study.

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

Legally Authorized Representative (LAR) (Sign and Name) Date

Person Obtaining Consent (Signature and Printed Name) Date

(In case of illiterate subjects)
Witness (Signature and Printed Name) Date

Annex 4: Consent - Survey, Legally Authorized Representatives of Minors

Background

The researchers, with the permission of Médecins Sans Frontières (MSF), the Ministry of Health (MSPP), and the Haitian National Bioethics Committee, would like to ask your relative some questions from a survey. About 400 women or their legal representatives who delivered a baby at this hospital will be asked to participate in the research study. The health care of your relative will not be affected by your decision to take part in the study or not.
The study will take place in a private place here in the hospital. The study involves an interview where we ask her about 40 questions. It will take about 30 minutes. She will be interviewed in private, and you would not be present.
The study will also use information routinely gathered from your relative and her baby's hospital chart.

Purpose

Pregnant women and newborn babies have a bigger risk of dying in Haiti than in many countries around the world. Problems that can happen during pregnancy or delivery can cause illness or death for a woman or baby.
At this time, we don't know why some women in Haiti have problems during their pregnancy or birth. We think there may be some factors that happen during the pregnancy that can affect whether or not she or her baby develops a problem. We think women who have less education, less financial support, or use a traditional midwife might have more problems. We would like to ask about your relative's life before she arrived here to the hospital. Her answers can help us to understand which factors might lead to problems for women or babies. The information we gather may help improve care in the future for pregnant women in Haiti.

What Happens In This Research Study

She will be one of approximately 400 subjects to be asked to complete a survey as part of the research study.

The research will take place here at The Emergency Obstetric Referral Hospital (CRUO), the hospital where your baby was born.

The study will take place in a private place here in the CRUO hospital. The study involves an interview where we ask your relative about 40 questions. It will take about 30 minutes. We will ask her questions about her life, your health, her pregnancy, and what she did before she came to the hospital.
The study will also use information routinely gathered from your relative and her baby's hospital chart. The researcher will record some information, including your relative and

her baby's medical diagnoses, from her medical chart after the interview.

Risks and Discomforts

There are very few risks to participating in this study. It may be upsetting for your relative to talk about her pregnancy or delivery if she or her baby had a problem. We can refer her to a mental health counsellor if she feels upset during the survey. You can also decide not to let her participate, or she can stop her participation, if you think she will feel upset. The time to participate may be an inconvenience.

There is a small risk that confidential but anonymous information that she tells us could be mistakenly shared with someone outside the research team. We will minimize this risk by not writing down her name or address on any forms.

There may be unknown risks/discomforts involved. Study staff will update you in a timely way on any new information that may affect your health, welfare, or decision to stay in this study.

Potential Benefits

Neither you nor your relative will receive direct benefit from her participation in this study. However, her participation may help the investigators better understand why some women have problems during their labor or delivery.

Alternatives

Your alternative is to not participate in the study.

Subject Costs and Payments

There are no costs to you for participating in this research study. You will not be paid to participate in this research study.

Confidentiality

Personal information will be kept confidential and will not be shared with anyone outside the study. We will not write your relative's name or address down, and we will not be able to identify her from the answers she gives us. Only people working on the study will be able to view her information. All of her answers, and this form, will be kept in a locked file here at the hospital, and then destroyed 3 years after the end of the research. Information from this study and from your relative's medical record may be used for research purposes and may be published; however, her name will not be used in any publications.

Subject's Rights

By consenting to participate in this study you do not waive any of your legal rights. Giving consent means that you have heard or read the information about this study and that you agree for your relative to participate. You will be given a copy of this form to keep.

If at any time you withdraw from this study neither you or your relative will suffer any penalty or lose any benefits to which you are entitled.

You may obtain further information about your rights as a research subject by calling the Office of the Institutional Review Board of Boston University Medical Center at 001-617-638-7207. You can also contact the Haitian Ethical Review Board at +509 3701 5166, or the office of Médecins Sans Frontières at +509 2811 0110.

The investigator or a member of the research team will try to answer all of your questions. If you have questions or concerns at any time, or if you need to report an injury while participating in this research, contact Katharine Hutchinson, BA, MSN, CNM, at +509 4892 7531 during the day or after hours.

Right to Refuse or Withdraw

Taking part in this study is voluntary. You have the right to refuse to take part in this study for any reason. If you decide to be in the study and then change your mind, you can withdraw your relative from the research at any time, and for any reason. Your participation is completely up to you. Your decision will not affect your relative being able to get health care at this institution or payment for your health care.

If you choose to take part, your relative has the right to stop at any time. If there are any new findings during the study that may affect whether you or your relative want to continue to take part, you will be told about them as soon as possible.

The investigator may decide to discontinue your relative's participation without your permission because he/she may decide that staying in the study will be bad for your relative, or the sponsor may stop the study.

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

Legally Authorized Representative (LAR) (Sign and Name) Date

Person Obtaining Consent (Signature and Printed Name) Date

(In case of illiterate subjects)
Witness (Signature and Printed Name) Date

Annex 5: Consent - In-depth interview, Legally Authorized Representative

Background

The researchers, with the permission of Médecins Sans Frontières (MSF), the Ministry of Health (MSPP), and the Haitian National Bioethics Committee, would like to ask you some questions during an interview about your relative. About 30 women or their legal representatives who delivered a baby at this hospital will be asked to participate in the research study. The health care of your relative will not be affected by your decision to take part in the study or not.
The study will take place in a private place here in the hospital. The study involves an interview where we ask you questions about your relative and her life. It will take about 60 minutes.

Purpose

Pregnant women and newborn babies have a bigger risk of dying in Haiti than in many countries around the world. Problems that can happen during pregnancy or delivery can cause illness or death for a woman or baby.
At this time, we don't know why some women in Haiti have problems during their pregnancy or birth. We think there may be some factors that happen during the pregnancy that can affect whether or not she or her baby develops a problem. We think women who have less education, less financial support, or use a traditional midwife might have more problems. We would like to ask you about your relative's life before she arrived here to the hospital. Your answers can help us to understand which factors might lead to problems for women or babies. The information we gather may help improve care in the future for pregnant women in Haiti.

What Happens In This Research Study

You will be one of about 30 women or legal representatives to be asked to complete an interview as part of this research study.

The research will take place here at The Emergency Obstetric Referral Hospital (CRUO), the hospital where your baby was born.

The study will take place in a private place here in the CRUO hospital. The study involves an interview where we ask you questions about your relative and her life. It will take about 60 minutes. We will ask you questions about your relative's life, her health, her pregnancy, and what she did before you came to the hospital. We will ask you about what she did before she came to the hospital, how she made the decision to come, what barriers she may have faced, and who helped her.
The study will also use information routinely gathered during for your relative and her

baby's hospital chart. The researcher will record some information, including her and her baby's medical diagnoses, from the medical chart after the interview.

Risks and Discomforts

There are very few risks to participating in this study. It may be upsetting to talk about your relative's pregnancy or delivery if she or her baby had a problem. We can refer you to a mental health counsellor if you feel upset during the survey. You can also decide not to participate, or to stop your participation, if you think you will feel upset. The time to participate may be an inconvenience.

There is a small risk that confidential but anonymous information that you tell us could be mistakenly shared with someone outside the research team. We will minimize this risk by not writing down your or your relative's name or address on any forms.

There may be unknown risks/discomforts involved. Study staff will update you in a timely way on any new information that may affect your relative's health, welfare, or decision to stay in this study.

Potential Benefits

Neither you nor your relative will receive direct benefit from your participation in this study. However, your participation may help the investigators better understand why some women have problems during their labor or delivery.

Alternatives

Your alternative is to not participate in the study.

Subject Costs and Payments

There are no costs to you for participating in this research study. You will not be paid to participate in this research study.

Confidentiality

Personal information will be kept confidential and will not be shared with anyone outside the study. We will not write yours or your relative's name or address down, and we will not be able to identify you or your relative from the answers you give us. Only people working on the study will be able to view your information. All of your answers, and this form, will be kept in a locked file here at the hospital, and then destroyed 3 years after the end of the research.
Information from this study and from your medical record may be used for research purposes and may be published; however, yours or your relative's name will not be used in any publications.

Subject's Rights

By consenting to participate in this study you do not waive any of your legal rights. Giving consent means that you have heard or read the information about this study and that you agree to participate. You will be given a copy of this form to keep.

If at any time you withdraw from this study you will not suffer any penalty or lose any benefits to which you or your relative are entitled.

You may obtain further information about your rights as a research subject by calling the Office of the Institutional Review Board of Boston University Medical Center at 001-617-638-7207. You can also contact the Haitian Ethical Review Board at +509 3701 5166, or the office of Médecins Sans Frontières at +509 2811 0110.

The investigator or a member of the research team will try to answer all of your questions. If you have questions or concerns at any time, or if you need to report an injury while participating in this research, contact Katharine Hutchinson, BA, MSN, CNM, at +509 4892 7531 during the day or after hours.

Right to Refuse or Withdraw

Taking part in this study is voluntary. You have the right to refuse to take part in this study for any reason. If you decide to be in the study and then change your mind, you can withdraw from the research at any time, and for any reason. Your participation is completely up to you. Your decision will not affect your relative being able to get health care at this institution or payment for your health care.

If you choose to take part, you have the right to stop at any time. If there are any new findings during the study that may affect whether you want to continue to take part, you will be told about them as soon as possible.

The investigator may decide to discontinue your participation without your permission because he/she may decide that staying in the study will be bad for you, or the sponsor may stop the study.

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

Legally Authorized Representative (LAR) (Sign and Name) Date

Person Obtaining Consent (Signature and Printed Name) Date

(In case of illiterate subjects)
Witness (Signature and Printed Name) Date

Annex 6: Consent - In-depth interview, Legally Authorized Representative of Minor

Background

The researchers, with the permission of Médecins Sans Frontières (MSF), the Ministry of Health (MSPP), and the Haitian National Bioethics Committee, would like to ask your relative some questions during an interview. About 30 women or their legal representatives who delivered a baby at this hospital will be asked to participate in the research study. The health care of your relative will not be affected by your decision to take part in the study or not.
The study will take place in a private place here in the hospital. The study involves an interview where we ask you questions about yourself and your life. It will take about 60 minutes. She will be interviewed in private, and you would not be present.

Purpose

Pregnant women and newborn babies have a bigger risk of dying in Haiti than in many countries around the world. Problems that can happen during pregnancy or delivery can cause illness or death for a woman or baby.
At this time, we don't know why some women in Haiti have problems during their pregnancy or birth. We think there may be some factors that happen during the pregnancy that can affect whether or not she or her baby develops a problem. We think women who have less education, less financial support, or use a traditional midwife might have more problems. We would like to ask about your relative's life before she arrived here to the hospital. Her answers can help us to understand which factors might lead to problems for women or babies. The information we gather may help improve care in the future for pregnant women in Haiti.

What Happens In This Research Study

Your relative will be one of approximately 30 subjects to be asked to complete an interview as part of the research study.

The research will take place here at The Emergency Obstetric Referral Hospital (CRUO), the hospital where your baby was born.

The study will take place in a private place here in the CRUO hospital. The study involves an interview where we ask your relative questions about herself and her life. It will take about 60 minutes. We will ask her questions about her life, your health and her pregnancy- including about what she did before you came to the hospital, how she made the decision to come, what barriers she may have faced, and who helped her.

Risks and Discomforts

There are very few risks to participating in this study. It may be upsetting for your

relative to talk about her pregnancy or delivery if she or her baby had a problem. We can refer her to a mental health counsellor if she feels upset during the survey. You can also decide not to let her participate, or she can stop your participation, if you think she will feel upset. The time to participate may be an inconvenience.

There is a small risk that confidential but anonymous information that she tells us could be mistakenly shared with someone outside the research team. We will minimize this risk by not writing down her name or address on any forms.

There may be unknown risks/discomforts involved. Study staff will update you in a timely way on any new information that may affect your relative's health, welfare, or decision to stay in this study.

Potential Benefits

Neither you nor your relative will receive direct benefit from her participation in this study. However, her participation may help the investigators better understand why some women have problems during their labor or delivery.

Alternatives

Your alternative is to not participate in the study.

Subject Costs and Payments

There are no costs to you for participating in this research study. You will not be paid to participate in this research study.

Confidentiality

Personal information will be kept confidential and will not be shared with anyone outside the study. We will not write your relative's name or address down, and we will not be able to identify her from the answers she gives us. Only people working on the study will be able to view her information. All of her answers, and this form, will be kept in a locked file here at the hospital, and then destroyed 3 years after the end of the research. Information from this study and from your relative's medical record may be used for research purposes and may be published; however, her name will not be used in any publications.

Subject's Rights

By consenting to participate in this study you do not waive any of your legal rights. Giving consent means that you have heard or read the information about this study and that you agree for your relative to participate. You will be given a copy of this

form to keep.

If at any time you withdraw from this study neither you or your relative will suffer any penalty or lose any benefits to which you are entitled.

You may obtain further information about your rights as a research subject by calling the Office of the Institutional Review Board of Boston University Medical Center at 001-617-638-7207. You can also contact the Haitian Ethical Review Board at +509 3701 5166, or the office of Médecins Sans Frontières at +509 2811 0110.

The investigator or a member of the research team will try to answer all of your questions. If you have questions or concerns at any time, or if you need to report an injury while participating in this research, contact Katharine Hutchinson, BA, MSN, CNM, at +509 4892 7531 during the day or after hours.

Right to Refuse or Withdraw

Taking part in this study is voluntary. You have the right to refuse to take part in this study for any reason. If you decide to be in the study and then change your mind, you can withdraw your relative from the research at any time, and for any reason. Your participation is completely up to you. Your decision will not affect your relative being able to get health care at this institution or payment for your health care.

If you choose to take part, your relative has the right to stop at any time. If there are any new findings during the study that may affect whether you or your relative want to continue to take part, you will be told about them as soon as possible.

The investigator may decide to discontinue your relative's participation without your permission because he/she may decide that staying in the study will be bad for your relative, or the sponsor may stop the study.

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

Legally Authorized Representative (LAR) (Sign and Name) Date

Person Obtaining Consent (Signature and Printed Name) Date

(In case of illiterate subjects)
Witness (Signature and Printed Name) Date

Annex 7: Assent - Survey, Minor Participants

Background

The researchers, with the permission of Médecins Sans Frontières (MSF), the Ministry of Health (MSPP), and the Haitian National Bioethics Committee, would like to ask you some questions from a survey. Because you are under age 18, we will ask both you and your legal guardian for consent for your participation. About 400 women who delivered a baby at this hospital will participate in the research study. Your care will not be affected by your decision to take part in the study or not.
The study will take place in a private place here in the hospital. The study involves an interview where we ask you about 40 questions. It will take about 30 minutes.
The study will also use information routinely gathered from you and your baby's hospital chart.

Purpose

Pregnant women and newborn babies have a bigger risk of dying in Haiti than in many countries around the world. Problems that can happen during pregnancy or delivery can cause illness or death for a woman or baby.
At this time, we don't know why some women in Haiti have problems during their pregnancy or birth. We think there may be some factors that happen during the pregnancy that can affect whether or not she or her baby develops a problem. We think women who have less education, less financial support, or use a traditional midwife might have more problems. We would like to ask you about your life before you arrived here to the hospital. Your answers can help us to understand which factors might lead to problems for women or babies. The information we gather may help improve care in the future for pregnant women in Haiti.

What Happens In This Research Study

You will be one of about 400 women to be asked to participate at this location.

The research will take place at The Emergency Obstetric Referral Hospital (CRUO), the hospital where your baby was born.

The study will take place in a private place here in the CRUO hospital. The study involves an interview where we ask you questions about yourself and your life. It will take about 30 minutes. We will ask you questions about your life, your health, your pregnancy, and what you did before you came to the hospital.

Risks and Discomforts

There are very few risks to participating in this study. It may be upsetting to talk about

your pregnancy or delivery if you or your baby had a problem. We can refer you to a mental health counsellor if you feel upset during the survey. You can also decide not to participate, or to stop your participation, if you think you will feel upset. The time to participate may be an inconvenience.

There is a small risk that confidential but anonymous information that you tell us could be mistakenly shared with someone outside the research team. We will minimize this risk by not writing down your name or address on any forms.

There may be unknown risks/discomforts involved. Study staff will update you in a timely way on any new information that may affect your health, welfare, or decision to stay in this study.

Potential Benefits

You will receive no direct benefit from your participation in this study. However, your participation may help the investigators better understand why some women have problems during their labor or delivery.

Alternatives

Your alternative is to not participate in the study.

Subject Costs and Payments

There are no costs to you for participating in this research study. You will not be paid to participate in this research study.

Confidentiality

Personal information will be kept confidential and will not be shared with anyone outside the study. We will not write your name or address down, and we will not be able to identify you from the answers you give us. Only people working on the study will be able to view your information. All of your answers, and this form, will be kept in a locked file here at the hospital, and then destroyed 3 years after the end of the research. Information from this study and from your medical record may be used for research purposes and may be published; however, your name will not be used in any publications.

Subject's Rights

By assenting to participate in this study you do not waive any of your legal rights. Giving consent means that you have heard or read the information about this study and that you agree to participate. You will be given a copy of this form to keep.

If at any time you withdraw from this study you will not suffer any penalty or lose any benefits to which you are entitled.

You may obtain further information about your rights as a research subject by calling the Office of the Institutional Review Board of Boston University Medical Center at 001-617-638-7207. You can also contact the Haitian Ethical Review Board at +509 3701 5166, or the office of Médecins Sans Frontières at +509 2811 0110.

The investigator or a member of the research team will try to answer all of your questions. If you have questions or concerns at any time, or if you need to report an injury while participating in this research, contact Katharine Hutchinson, BA, MSN, CNM, at +509 4892 7531 during the day or after hours.

Right to Refuse or Withdraw

Taking part in this study is voluntary. You have the right to refuse to take part in this study for any reason. If you decide to be in the study and then change your mind, you can withdraw from the research for any reason, at any time. Your participation is completely up to you. Your decision will not affect your being able to get health care at this institution or payment for your health care.

If you choose to take part, you have the right to stop at any time. If there are any new findings during the study that may affect whether you want to continue to take part, you will be told about them as soon as possible.

The investigator may decide to discontinue your participation without your permission because he/she may decide that staying in the study will be bad for you, or the sponsor may stop the study.

Signing this assent form indicates that you have read this assent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed assent form.

Child Assent (Signature and Printed Name) Date

Person Obtaining Consent (Signature and Printed Name) Date

(In case of illiterate subjects)
Witness (Signature and Printed Name) Date

Annex 8: Assent - In-depth interview, Minor Participants

Background

The researchers, with the permission of Médecins Sans Frontières (MSF), the Ministry of Health (MSPP), and the Haitian National Bioethics Committee, would like to ask you some questions during an interview. Because you are under age 18, we will ask both you and your legal guardian for consent for your participation. Women who delivered a baby at this hospital will participate in the research study. Your care will not be affected by your decision to take part in the study or not.
The study will take place in a private place here in the hospital. The study involves an interview where we ask you questions about yourself and your life. It will take about 60 minutes.

Purpose

Pregnant women and newborn babies have a bigger risk of dying in Haiti than in many countries around the world. Problems that can happen during pregnancy or delivery can cause illness or death for a woman or baby.
At this time, we don't know why some women in Haiti have problems during their pregnancy or birth. We think there may be some factors that happen during the pregnancy that can affect whether or not she or her baby develops a problem. We would like to ask you about your life before you arrived here to the hospital. Your answers can help us to understand which factors might lead to problems for women or babies. The information we gather may help improve care in the future for pregnant women in Haiti.

What Happens In This Research Study

You will be one of about 30 women to be asked to participate at this location.

The research will take place at The Emergency Obstetric Referral Hospital (CRUO), the hospital where your baby was born.

The study will take place in a private place here in the CRUO hospital. The study involves an interview where we ask you questions about yourself and your life. It will take about 60 minutes. We will ask you questions about your life, your health and your pregnancy - including what you did before you came to the hospital, how you made the decision to come, what barriers you may have faced, and who helped you.

Risks and Discomforts

There are very few risks to participating in this study. It may be upsetting to talk about your pregnancy or delivery if you or your baby had a problem. We can refer you to a

mental health counsellor if you feel upset during the survey. You can also decide not to participate, or to stop your participation, if you think you will feel upset. The time to participate may be an inconvenience.

There is a small risk that confidential information that you tell us could be mistakenly shared with someone outside the research team. We will minimize this risk by not writing down your name or address on any forms.

There may be unknown risks/discomforts involved. Study staff will update you in a timely way on any new information that may affect your health, welfare, or decision to stay in this study.

Potential Benefits

You will receive no direct benefit from your participation in this study. However, your participation may help the investigators better understand why some women have problems during their labor or delivery.

Alternatives

Your alternative is to not participate in the study.

Subject Costs and Payments

There are no costs to you for participating in this research study. You will not be paid to participate in this research study.

Confidentiality

Personal information will be kept confidential and will not be shared with anyone outside the study. We will not write your name or address down, and we will not be able to identify you from the answers you give us. Only people working on the study will be able to view your information. All of your answers, and this form, will be kept in a locked file here at the hospital, and then destroyed 3 years after the end of the research. Information from this study and from your medical record may be used for research purposes and may be published; however, your name will not be used in any publications.

Subject's Rights

By assenting to participate in this study you do not waive any of your legal rights. Giving consent means that you have heard or read the information about this study and that you agree to participate. You will be given a copy of this form to keep.

If at any time you withdraw from this study you will not suffer any penalty or lose any

benefits to which you are entitled.

You may obtain further information about your rights as a research subject by calling the Office of the Institutional Review Board of Boston University Medical Center at 001-617-638-7207. You can also contact the Haitian Ethical Review Board at +509 3701 5166, or the office of Médecins Sans Frontières at +509 2811 0110.

The investigator or a member of the research team will try to answer all of your questions. If you have questions or concerns at any time, or if you need to report an injury while participating in this research, contact Katharine Hutchinson, BA, MSN, CNM, at +509 4892 7531 during the day or after hours.

Right to Refuse or Withdraw

Taking part in this study is voluntary. You have the right to refuse to take part in this study. If you decide to be in the study and then change your mind, you can withdraw from the research. Your participation is completely up to you. Your decision will not affect your being able to get health care at this institution or payment for your health care.

If you choose to take part, you have the right to stop at any time. If there are any new findings during the study that may affect whether you want to continue to take part, you will be told about them as soon as possible.

The investigator may decide to discontinue your participation without your permission because he/she may decide that staying in the study will be bad for you, or the sponsor may stop the study.

Signing this assent form indicates that you have read this assent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed assent form.

Child Assent (Signature and Printed Name) Date

Person Obtaining Consent (Signature and Printed Name) Date

(In case of illiterate subjects)
Witness (Signature and Printed Name) Date

Annex 9: Survey Questionnaire

Identifying Behavioral, Demographic and Clinical Risk Factors for Delayed Access to Emergency Obstetric Care in Preeclamptic Women in Port au Prince, Haiti

QUESTIONNAIRE NO:

DATE OF INTERVIEW: **TYPE OF RESPONDANT:**
PATIENT/LEGAL REPRESENTATIVE

DEMOGRAPHIC QUESTIONS
First we would like to ask you some questions about your background and your family.

What is your age?:

Where do you live? (Neighborhood, not exact address)
write response: _____

What is your marital status?
Never married
Married
Divorced/separated
Widowed
Co-habitating

What is your highest educational level attained?:
No formal education
Primary education
Secondary Education
University

What is your religion:
Catholic
Lutheran
Anglican
Protestant
Pentecostal
Seven Days Adventists (SDA)
Jehovah Witness
Traditional/Voudou
Muslim
No religion
Other, specify_____

What is your occupation?:
Housewife
Informal business
State employee
Employee

What is your housing situation?:
Owner
Renter
Squatter
Live with family/friends

Do you live in an IDP camp?
Yes
No

How would you describe your economic status?
Well-off
Middle class
OK
Very poor

Clinical Questions Prior to this Pregnancy
*Now we will ask you some questions about your health **before you were pregnant** with the baby you delivered here.*

Before this pregnancy, did you ever visit a doctor or hospital for a health problem?
Yes
No
Don't know/not sure

Before this pregnancy, were you ever diagnosed by a medical doctor with a health problem?
Yes
No
Don't know/not sure

If yes, what was/were the problem/s?
_____
_____
_____

(for women with a previous pregnancy- otherwise skip to next section- Current Pregnancy)

Did you ever get diagnosed with preeclampsia or high blood pressure during a previous pregnancy?
Yes
No
Don't know/not sure

Did you ever have any other major complication of pregnancy requiring hospitalization during a previous pregnancy?
Yes
No
Don't know/not sure

If yes: _____

For your most recent pregnancy before this one, where did you deliver?
Home
Health center
Hospital
TBA house
Other: _____

For your most recent pregnancy, if you did not deliver at the hospital or health center, why not?
Preferred to be at home
Preferred to be with matron
No hospital or health center available
Hospital or health center too expensive
Hospital or health center too far away
Too dangerous to access health center or hospital
Baby came too fast
Other:

Before this pregnancy, did you ever have a baby with one of the following problems?

Born prematurely
Yes
No
Don't know/not sure

Born too small
Yes
No
Don't know/not sure

Needed resuscitation at delivery
Yes
No
Don't know/not sure

Born dead
Yes
No
Don't know/not sure

Current Pregnancy Clinical Questions
Now we will ask you some questions about this pregnancy.

Did you receive prenatal care from a nurse or doctor during this pregnancy?
Yes
No
Don't know/not sure

How many times did you see a nurse or a doctor for a prenatal visit?
1
2
3
4
More than 4 times

Were you diagnosed with preeclampsia or high blood pressure during this pregnancy before you arrived to CRUO?
Yes
No
Don't know/not sure

Did a doctor or nurse diagnose you with any other problems during this pregnancy?
Yes
No
Don't know/not sure

If yes, what was/were the problem/s?
_____
_____
_____

Did a doctor or nurse advise you to go to the hospital for delivery?
Yes
No
Don't know/not sure

Did you visit a matrone (TBA) during this pregnancy?
Yes
No
Don’t know/not sure

How many times did you see a matron during this pregnancy?
1
2
3
4
More than 4 times

Did the matrone advise you to go to the hospital for delivery?
Yes
No
Don’t know/not sure

Did you take any medications during this pregnancy?
Yes *(if yes, skip next question)*
No
Don’t know/not sure

If you did not take medications during this pregnancy, why not?
(if they did not take medication, skip next question)
Didn’t have a health problem needing medicine
Did not see a doctor to get medicine
Did not know where I could get medicine
Could not afford medicine
Other: _____

If you did take medication during this pregnancy, did a doctor or nurse prescribe this medication?
Yes
No
Don’t know/not sure

Did a doctor or nurse tell you about danger signs of complications during this pregnancy?
Yes
No
Not sure/don't know

Will you please tell me some danger signs of high blood pressure (preeclampsia) in pregnancy?
(*Check all given responses)*

Headache
Swelling in hands or face
Visual changes
Epigastric pain (abdominal pain)
Convulsions
Other:

Utilization questions:
We will ask you some questions about what you did before you arrived here at the hospital.

While you were at home, before came to the hospital, did you realize you had a complication of pregnancy?
Yes
No
Not sure/don't know

Before you delivered the baby, how did you know you needed to access health care?
Feeling contractions
Feeling sick
Family member told me to come
Doctor/nurse told me to come
Felt the baby coming
Other: _____

After that decision, how long did it take before you left your house?
_____ (in hours)

Who made the decision to go to the hospital?
I did
My husband/partner
A family member
Matrone
Other:

Were there any tasks or events that delayed your leaving?
Yes
No
Not sure

If yes, please state: _____
Did anyone in your family (parents, partner, sister) encourage you to go seek care?
Yes
No
Unsure

Did anyone in your family discourage you from seeking care?
Yes
No
Unsure

Did you have to find money before traveling to the hospital?
Yes
No
Unsure
If yes, how much money?_____

After the decision to seek care, who was the first medical person you consulted?
Nurse
Doctor
Matrone
Did not consult medical person
Other: _____

After you decided you needed health care, did you visit another hospital or health center before you arrived here to this hospital?
Yes- one
Yes- more than one
No
Don't know/not sure

If yes, which hospital(s) or health center(s):

Did a medical person or medical structure refer you to this hospital?
Yes
No
Don't know/not sure

If yes, who or where referred you to this hospital?
Matrone
Doctor
University Hospital
Private hospital
NGO hospital
Public health clinic
Private health clinic
If you went to another medical structure, how long did you wait there to be seen by a doctor or nurse?
Was seen immediately
More than 30 minutes
Over 1 hour

Over 2 hours
No service

How many hours after you decided to see medical care did you arrive at the CRUO hospital (where you are now)? _____ (hours)

How did you travel to this hospital? *(choose all that apply)*
Walking
Taptap or other public transit
Motorcycle
Ambulance
Private car

How long does it generally take you to travel to this hospital from your home?
Less than 30 minutes
30 – 60 minutes
1 hour – 2 hours
More than 2 hours

How much does it cost for you to travel to this hospital from your home?

What is the closest hospital to your house that treats pregnant women with complications of pregnancy? _____

(If the woman went to a different hospital) Why did you not go to this hospital when you had a complication?
Too expensive
Too long to wait
Health care not good quality
Too far away
I don't like that hospital
Problem with transport
There was no one to go with me
My family did not want me to go there
I didn't know where to go
Other: _____

Before you arrived here, did you know this hospital offered free care?
Yes
No
Don’t know/not sure

Protection Questions:

Of the following, which is your greatest concern for yourself?
Access to health care
Security
Access to food
Access to housing
Not concerned

Do you feel safe at home?
Yes
No
Don't know/not sure

 INTERVIEWER: *Thank you very much for the information and your time!*

Annex 10: Qualitative Interview Guide

Identifying Behavioral, Demographic and Clinical Risk Factors for Delayed Access to Emergency Obstetrical Care in Preeclamptic Women in Port au Prince, Haiti

Qualitative In-depth Interview Guide, Adapted from Johns Hopkins Bloomberg School of Public Health materials [145]

Background to the study:
This study is trying to understand why some women in Port au Prince have a problem during their pregnancies. Some women have health problems for themselves or their babies. This research is trying to understand why some women have these problems. I will ask you some questions about what happened before you arrived at the hospital- you can stop at any time if you are uncomfortable.

General interview guidelines:
The topics and questions below should be used to guide the interview but can be adapted as necessary to each interview. Keep in mind when conducting the interview to respond to the answers provided by the respondent by asking additional questions to those proposed below or adapting to more appropriate questions.
Please offer to stop the questions if any woman appears upset by the conversation.
Remind subjects that they can withdraw at any time with no consequences to themselves.

Initial Question: "I would like to learn from you about the situations that pregnant women face. Please tell me about what happened before you arrived to the hospital?"

Follow up themes:
What the woman thought was happening to her before she arrived, what was her problem?

Home care practices, including traditional medications and religious customs, medications bought without prescriptions during the pregnancy?

The sequence and timing of home care practices.

Duration of symptoms prior to seeking care; symptoms that were given as the main reason for seeking care.

Name, location of the first health care facility to which the woman visited (first provider visited).

Who made the decision to first seek care? Did the woman decide herself? Did her partner or parents decide? Was there some discussion about when and where to go? How much time was spent on this? Who actually went with the woman for care?

Were there any obstacles to seeking care as quickly as the mother would have liked? (for example, lack of money, no transportation, etc.)

If more than one provider was visited, what was the sequence and timing of care seeking? What were the reasons for seeking care from more than one provider? When and how was the decision made to visit other providers?

What treatments did providers give? (Also note the use of any home remedies that were taken at the same time as medicines acquired from providers).

Were there any changes in symptoms (improving or worsening) after treatment from the first provider?

Was the mother satisfied with the care received from the different providers?

Did anyone give them advice about what to do for the woman (home care and care seeking)? Who? What advice did they give? Was there any other place the woman went for information or advice?

How does the woman explain the problem she or her baby had? What does she think is the cause? What could have made the situation different for someone else with the same problem to have a better outcome?

Annex 11: Medical Records Data Collection Form

Identifying Behavioral, Demographic and Clinical Risk Factors for Delayed Access to Emergency Obstetrical Care in Preeclamptic Women in Port au Prince, Haiti

Questionnaire Number:

Woman's Information

Age at admission:

Gravity/Parity:

Preeclampsia: Yes/No

Eclampsia: Yes/No if yes, # of eclamptic seizures: If yes: in hospital / prior to admission

Blood pressure on admission:

Admission to delivery interval (hours):

ICU admission: Yes/No

Blood transfusion: Yes/No

Cesarean section: Yes/No

Coma: Yes/No Glasgow coma score:

Multiple Gestation: Yes/No

Diabetes: Yes/No

Obesity: Yes/No

Infant Information

NICU admission: Yes/No

Gestational age (weeks) at Delivery:

Weight in grams:

APGAR score at 1 min/5 min:

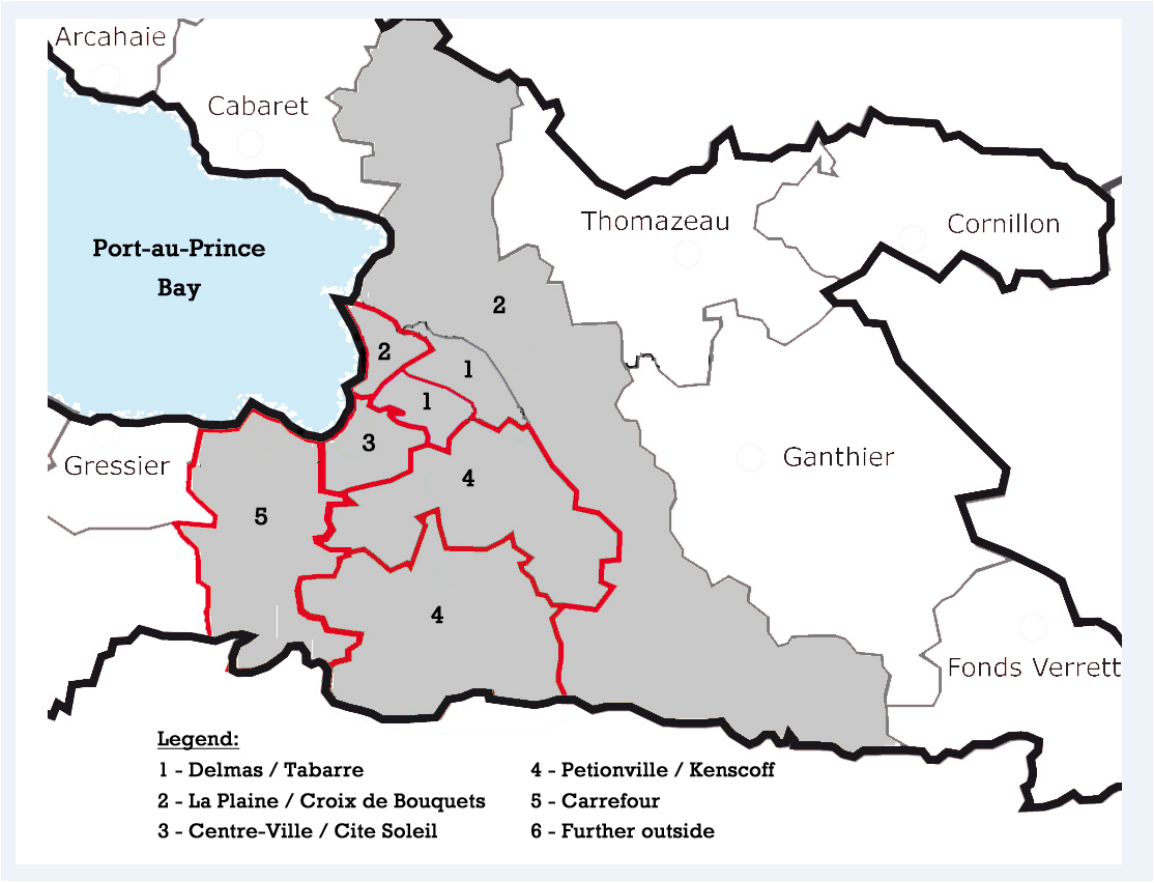
Fetal heartbeat on admission: Yes/No

Fetal heartbeat at delivery: Yes/No

Death after delivery of live infant: Yes/No

If yes, death after how many days of life:

Annex 12: Map of Port au Prince Neighborhoods



Annex 13: Description of Training for Research Assistants

The research assistants underwent a weeklong training in research ethics, study protocols, and qualitative interview techniques. The research ethics training was an open-source, online curriculum in French, "Introduction to Clinical Research", developed by the Global Health Trials Network. This global network is managed by a consortium of research universities around the world, and offers high-quality online courses in research methods and ethics. The course consisted of the following modules:

1. Introduction To Clinical Research
    1. Course Recognition
    2. Acknowledgements
    3. Course Objectives and Contents
    4. What Is Clinical Research?
    5. How Does Clinical Research Differ From Standard Care?
    6. Why Do We Perform Clinical Research (a)?
        1. Why Do We Perform Clinical Research (b)?
    7. Introduction: Key Points To Remember
    8. What Are The Main Principles Of Research Ethics (a)?
        1. What Are The Main Principles Of Research Ethics (b)?
    9. What Is Informed Consent And Why Is It Needed (a)?
        1. What Is Informed Consent And Why Is It Needed (b)?
        2. What Is Informed Consent And Why Is It Needed (c)?
        3. What Is Informed Consent And Why Is It Needed (d)?
        4. What Is Informed Consent and Why Is It Needed (e)?
    10. Why Do People Participate In Clinical Research And What Are The Benefits And Risks Involved (a)?
        1. Why Do People Participate In Clinical Research And What Are The Benefits And Risks Involved (b)?
    11. Research Ethics: Key Points To Remember
    12. Study Designs
    13. Cohort Studies
    14. Case Control Studies
    15. Cross Sectional Surveys

16. Case Reports
17. Clinical Trials (a)
    1. Clinical Trials (b)
18. Study Designs: Key Points To Remember
19. Maintaining High Ethical Standards, Data Quality And Uniformity In A Study (a)
    1. Maintaining High Ethical Standards, Data Quality And Uniformity In A Study (b)
20. Key Points To Remember
21. References And Resources
22. Quiz

The research assistants completed the online modules in French, and passed the quiz at the end. Prior to starting data collection, both research assistants engaged in role-playing activities with the PI, to ensure adequate comprehension of study survey protocols, informed consent procedures, data collection forms, confidentiality measures, and withdrawal procedures for the survey.

The qualitative research methods training is a 7-module course for Non-Governmental Organizations developed by the Johns Hopkins Bloomberg School of Public Health. Of the 7 modules, five were relevant to this study and were translated into French. The five modules include:

Section 1: Introduction to the Training in Qualitative Research Methods for PVOs/NGOs

Section 2: Overview of Qualitative Research

Section 3: Interviewing in Qualitative Research

Section 4: Qualitative Research Methods

Section 5: Management of Qualitative Data

Annex 14. Frequency distribution of first delay by preeclampsia status

Table 22. Frequency distribution of first delay by preeclampsia status

Hours of first delay	Normal Frequency Count n = 207	Preeclamptic Frequency Count n = 285
0	31	100
1	43	32
2	27	12
3	23	12
4	18	14
5	18	7
6	12	5
7 - 10	9	26
11-20	11	25
21-30	10	21
31-100	5	25
>100	-	6

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CURRICULUM VITAE

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EDUCATION

Boston University School of Public Health, Boston, USA
Anticipated 2016, Doctor of Public Health, Global Health concentration
Coursework including needs assessment, program design and evaluation, leadership and management, health economics, financial management, quality improvement, and quantitative and qualitative research methods.

Yale University School of Nursing, New Haven, USA
May 2005, Masters in Nursing
Nurse Midwifery Specialty

Swarthmore College, Swarthmore, USA
June 2001, Bachelor of Arts
Major in Psychology and Education, Concentration in Women's Studies

WORK EXPERIENCE

Pathfinder International, Watertown, MA
Senior Technical Advisor for Sexual and Reproductive Health and Rights
January 2016- present
Maternal and Newborn Health technical advice to advance Pathfinder field programs, proposals, and technical visibility.

Doctors Without Borders/Médecins Sans Frontières (MSF)
Collaborated with MSF from 2009 to 2014 in clinical, department management, and program administration capacities. Main areas of focus included public health surveillance, maternal and reproductive health services, child malnutrition, physical and sexual violence, and community outreach. Extensive experience regarding health care provision in conflict zones. MSF assignments as follows:

- *Port au Prince, Haiti.* December 2013- July 2014

Public Health Surveillance Officer for MSF Coordination. Monitoring of health and humanitarian emergencies countrywide. Collaboration and networking with governmental, NGO, and multilateral donor partners. Collaborated to plan and

implement surveillance activities for cholera nationwide, and for maternal and child health issues in Port au Prince. Investigated and planned MSF response to ongoing emergencies, including IDP camps.

- *South Kordofan, Sudan.* March 2012-July 2012

Supervision and management of four health care centers, four outpatient malnutrition programs, and one inpatient hospital in active conflict zone.

- *Abéché, Chad.* July 2011-December 2011

Supervision and management of maternity unit in collaboration with Ministry of Health colleagues. Implementation of training and procedures to reduce maternal and infant mortality in one of three Chadian referral hospitals.

- *Agok, South Sudan.* August 2010-February 2011

Supervision and management of maternity unit of MSF hospital in the contested Abyei border region.

- *Dungu, Democratic Republic of the Congo.* October 2009- May 2010

Management of MSF outpatient activities for populations affected by Lord's Resistance Army violence. Supervision of outpatient health centers, malnutrition programs, community health worker program, and mobile clinics.

ICS/Integrare, Barcelona, Spain
Researcher, Doctoral Practicum - August, September 2013
Consultant - November, December 2013

Worked collaboratively to develop and elaborate Midwifery Services Framework for the International Confederation of Midwives, by researching tools and resources to increase women's access to quality maternity services in low resource settings. Researched and consolidated evidence based antenatal and postnatal care for Gates-funded grant. Development of conceptual framework to guide research of care practices.

Mt. Auburn Hospital, Cambridge, USA
Midwife - September 2012-present

Full-scope, independent management of midwifery patients in outpatient and inpatient settings.

Cambridge Health Alliance, Cambridge, USA
Midwife - March 2006-September 2009

Independent management of obstetric and gynecologic caseload of low risk women, management of high risk cases collaboratively with physician colleagues. Intrapartum practice in a hospital and an out-of-hospital birth center with largely immigrant and low-income population. Initial newborn care and infant resuscitation in birth center practice.

RESEARCH EXPERIENCE

Doctoral Dissertation. "Identifying Behavioral, Demographic and Clinical Risk Factors for Delayed Access to Emergency Obstetrical Care in Preeclamptic Women in Port au Prince, Haiti." Quantitative survey and qualitative in-depth interviews.

Graduate Thesis, 2005. Qualitative study of midwives' responses to client demands for technology and intervention during the birth process. Recommendations for midwives in discussing elective primary cesarean sections.

Undergraduate Thesis, 2000. Qualitative study of UNFPA education program for adolescents in Kathmandu, Nepal.

FACULTY EXPERIENCE

Yale University School of Nursing, New Haven, USA
January 2008- May 2009
Preceptor of Yale University midwifery students in full scope midwifery practice

HONORS AND AWARDS

Boston University Women's Guild, Katherine Connor McLaughlin Scholarship for doctoral dissertation research

Tinker Field Research Grant for master's thesis research in Esteli, Nicaragua

Eugene M. Lang Summer Initiative Award, William L. Huganir Summer Research Stipend for Population Research for undergraduate thesis research in Nepal

LANGUAGES

Native English speaker
Excellent verbal and written communication in French

LICENSING

Current Nursing and Midwifery License in Massachusetts
Current Drug Enforcement Administration (DEA) License