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Obstetric Fistula: The Experiences of Patients and Medical Personnel in Sierra Leone

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Abstract

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MA, Argosy University, 2010

BA, Fourah Bay College, 2003

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

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Abstract

Women face great risks in pregnancy and childbirth, especially in developing countries where there are very few skilled birth attendants and negligible government investments in maternal health programs. As a result, obstetric fistula (OF), a potentially fatal but preventable and treatable condition, affects some 3 million women and girls globally. In Sierra Leone, the prevalence of OF is extremely high, but the absence of quality data to inform decision-making, both on prevalence and risk factors, is a barrier to creating an environment for OF prevention and care. The purpose of this phenomenological study was to explore and document the barriers to medical care, and the perceptions of patients and medical personnel concerning the complexities of OF. In-depth interviews were performed over a 2-month period with 12 patients and 8 medical personnel at the Aberdeen Women's Center in Freetown, Sierra Leone. Results showed that patients face multiple medical barriers including high costs, fear of hospital treatment, severely inadequate treatment, and severe physical sequelae including paralysis and foot dragging. Multiple emotional, social, and financial harms related to OF were also reported, including stigmatization, abandonment by family, embitterment, depression, and job loss. Most patients expressed a preference for traditional birth assistants over medical personnel. However, many also benefitted from the intervention of friends or other good Samaritans. The results and recommendations from this study should be helpful in informing the general public and policy-makers about OF as a major public health problem, and in the design and delivery of programs to eradicate or alleviate the problem of OF in Sierra Leone.

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Dedication

I respectfully dedicate my dissertation to the loving memories of my mother, Hawa Doponjo Samba and father, Sheku Samba whose passion for education paved the way for my academic journey even though both never ventured into it. May their souls rest in perfect peace. To my beloved uncle, Mohamed Aruna Kanneh, who has remained my most trusted confidant from tender age I can proudly pronounce you as my hero for taken the bold step as a village teacher to initiate me to western education. The first step you took to share my worries, stresses and responsibilities from tender age to university epitomizes the beauties of extended family system. With your lovely kindness and unwavering support, the idea of being an orphan was far remote from me. I have ever known you as my everything and you instilled in me the spirit of kindness, respect, contempt, and determination for which I am very grateful. This journey would not have been also possible without the love and support of my wife, Grace, daughter Samantha and many friends particularly Joshua Murray who continued to encourage me throughout.

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Chapter 1: Introduction to This Study

Introduction

The World Health Organization's (WHO, 2014) fifth Millennium Development Goal (MDG 5) is targeted to improving maternal health (WHO, 2014). In 2013 alone, 289,000 women died in childbirth worldwide, with 62% in sub-Saharan Africa, where the maternal mortality rate is 510 per 100,000 live births. The country with the worst record for maternal mortality is Sierra Leone, where an estimated 1,100 mothers die per 100,000 live births (WHO, 2014). The lifetime risk for a woman in Sierra Leone of dying from childbirth complications is 1 in 21, implying that almost 5% of all women will die from these causes.

In addition to mortality, a key complication suffered by women in childbirth is that of obstructed labor, which can go on for several days. In most cases of obstructed labor (58–95%, depending on the study), a woman tries to deliver at home and is later transferred to a health facility for delivery (Tebeu et al., 2012). When childbirth occurs outside of healthcare centers or without competent birth assistants or midwives on hand, such prolonged labor can result in an obstetric fistula—a condition in which the fetus pressing against the pelvis forces the vaginal wall to rupture (Wall, 2012a). These fistulas result in holes between the vagina and the urethra and/or between the vagina and the rectum and result in unconstrained leakage of urine or feces, or both (Wall, 2012a). Since delays in effective intervention in the birth increases the time the child presses against the pelvis, longer delays in reaching competent emergency obstetric care have been associated with an increase in the occurrence of obstetric fistulas (Tebeu et al., 2012).

Other factors associated with increased risk of obstetric fistulas include teenage status at delivery, primiparity, home delivery, and being less than 150 cm (4 ft. 9 in.) tall (Tebeu et al., 2012).

If untreated, the physical experiences of these preventable fistulas include incontinence in urine or feces, or both, continual unacceptable odors from that leakage, ongoing urinary infections, infertility, loss of sexuality, foot-drop if nerve damage also occurs, chronic pelvic pain, and chronic vulvar dermatitis (Wall 2012a). The social experiences are equally severe, including depression, shunning by the community, friends, family, and husbands, loss of jobs and thus loss of income, and, understandably, post-traumatic stress disorders (Wall, 2012a). Many of these women are reduced to beggary to survive. De Bernis (2007) has estimated that more than 2 million women suffer from chronic obstetric fistulas, with most of them in sub-Saharan Africa and the poorer parts of Asia. By 2011, that estimate had increased to 3.5 million women (Rai, 2011).

Obstetric fistulas are both preventable and treatable. Prevention happens when mothers receive proper care during childbirth via competent birth assistance, potentially including cesarean sections to eliminate prolonged labor (Warren & Mwangi, 2008). Such obstetric assistance can save the life of both mother and child; generally, the child dies in 90% of obstructed and prolonged labors (Wall, 2012a). Treatment consists of surgical repair of the fistulas, though it sometimes requires multiple surgeries to get a complete resolution of the problem (Wall, 2012a). Recent studies have also found that despite surgical repair, some long-term experiences, such as ongoing urinary tract

infections, remain very common in these women (Wondimeneh et al., 2014). This situation is especially tragic given that obstetric fistula is almost entirely preventable with appropriate medical care during delivery, and it is treatable with timely and appropriate surgical repair of the fistulas after they develop.

The next section includes a detailed background of obstetric fistula as it pertains to this study. Next, I describe the specific problem studied in this investigation. That section is followed by a brief statement of the purpose of this study, including the research paradigm that guided the investigation. Next, I present the two guiding frameworks for this research, the availability, accessibility, acceptability, quality (AAAQ) model and the three delay model, along with an explanation of how I used those two frameworks. A brief description of the nature of this study follows, which anticipates the more detailed description of methods presented in Chapter 3. I also define some key terms used in this study to ease understanding and to show how I used the terms in this study. Finally, I present the assumptions underlying the study, the scope and delimitations of the study, the limitations of the study design, and the significance of the study.

Background

Obstetric fistula is one of the most neglected, devastating, and under-documented reproductive health problems among adolescents and women in poor countries (Semere & Nour, 2008). Alkire et al. (2012) regards it as a public health epidemic. It is especially common in the northern half of Sub-Sahara Africa and South Asia, sometimes known as "the fistula belt," where economic insecurity, social instability, and institutional

mismanagement are common. The United Nations Population Fund (UNPF) has estimated that up to 3 million women and girls live with fistula globally, with 50,000–130,000 cases occurring in Africa annually (Alkire et al., 2012). It is generally regarded as a catastrophic childbirth injury that occurs when there is a long obstructed labor—lasting for a day or more—without access to emergency medical intervention or cesarean section (Meyer et al., 2007). Under such circumstances, an abnormal opening occurs between the vagina and the rectum or bladder, which allows involuntary discharge of urine into the vaginal vault (Forsgren, 2009). In most cases the baby dies and the mother lives with fistula, rendering her incapable of holding urine or feces. Even though obstetric fistula affects women of all ages, the most at-risk remain primigravid adolescent girls.

There has been a virtual elimination of this condition in industrial countries due to improved and universal access to emergency obstetric care and the availability of skilled birth attendants (Warren & Mwangi, 2008). Conversely, in developing countries this condition remains where the health care sector is poorly resourced, and access to quality and affordable maternal health services remains a challenge. This is further compounded by chronic illiteracy, a culture of home delivery by unskilled birth attendants, the practice of female genital mutilation, early child marriage, and the widespread lack of health decision-making power of women (Zheng & Anderson, 2008). Where these conditions are prevalent, the incidence of obstetric fistula and maternal mortality is always common.

In addition to the incontinence that characterizes obstetric fistula, victims also suffer dehumanizing conditions like vulva irritation, urinary tract infections, nerve damage, and kidney failure, especially if the condition is protracted without surgical

intervention (Wall et al., 2004). Fistula can also lead to maternal death when no medical attention is sought for a long time (Abouzahr, 2003). The agonies endured from offensive body odor emanating from the leaking of urine and/or feces also cause victims to be psychologically depressed, particularly if it leads to infertility. In this situation, where societal perception is incompatible with biomedical wisdom and there is no knowledge about repair, victims are often blamed. Thus, they have to live not only with the pungent smell of urine, lack of sexual activity, inability to give birth, and the economic blows they suffer, but they are faced with divorce and become social outcasts (Adler et al., 2013). With the failure to attain social reintegration, they are relegated to the margins of society and often can survive only by begging.

With a functional health system—with available and accessible emergency obstetric care services, a sound and effective referral/evacuation system, skilled birth attendants, and educational programs that discourage early marriages and sexual activities for young adolescents—obstetric fistula can be prevented (UNPF, 2012). However, there are multiple barriers to creating such an environment, the most important currently being the absence of quality data to inform decision-making. This is the case in Sierra Leone, which is one of the poorest countries in the world with the highest maternal mortality rate (UNPF, 2012). As Abouzahr (2003) observed, sound information is crucial for health action, and the absence of data on the dimensions of this disease, including its impact and significance, hinders the creation of advocacy or appropriate intervention.

The gaps I identified in the literature include the few studies done to define the best practices for surgical techniques to repair the fistulas. The management of symptoms

of the disease before and after surgery is also significantly understudied. Again, there is an absence of quality data to inform decision-making, which continues to serve as a barrier to creating the enabling environment for the prevention and care of fistulas in Sierra Leone. Since this study is the first to address the phenomenological experiences of women in Sierra Leone who have obstetric fistulas, it will contribute to those data. This will give insight into the risk factors, the reasons for the delays to seek care, and the population that is most at risk, and it will render a new and positive orientation that will hopefully impact public perception and ultimately change behavior.

Problem Statement

Obstetric fistula is a hole that develops either between the rectum and vagina or between the bladder and vagina after severe or failed childbirth. It occurs when adequate medical care is not available and is one of the most hidden and preventable public health problems to afflict women and girls in post-conflict Sierra Leone, where poverty is common and access to family planning and quality health services is abysmally low. In Sierra Leone, there are few skilled birth attendants and negligible government investment in maternal health programs (Melah et al., 2007).

In such a setting, poor institutional capacity to provide emergency obstetric services, diagnosis, or treatment in a timely fashion results in routine death or disability from complications of pregnancy and childbirth (Roka et al., 2013). A prolonged and obstructed labor often results in an obstetric fistula, which renders women incontinent (Browning, 2004). Malnourished women are at an especially high risk (Melah et al., 2007).

With society largely ignorant about fistula and its associated experiences, the cause is often considered to be personal immoral behavior (Wall, 2012). This leads to the stigmatization and ostracism of afflicted women, which in turn sets the stage for divorce and eventual isolation by family and community members (Browning, 2004). This unbearable situation relegates victims of a fistula to the margins of society, with no hope of returning to full and productive lives. With no access to health services, victims suffer depression, post-traumatic stress disorder, social isolation, and in most cases harbor suicidal ideation (Wall, 2012).

According to the UNPF, more than 3 million women and girls live with this condition globally, with Africa accounting for a lion's share each year (Alkire et al., 2012). Tackling the incidence of obstetric fistula requires increased knowledge about the risk factors that make women susceptible and the agonies they endure while living with the condition. With increased knowledge, the need for intervention by health policy makers and public health advocates will become evident and may spur policies that increase community midwife training to reduce the high rates of birth attended by unskilled assistants.

Purpose of the Study

The purpose of this research was to use a phenomenological approach to understanding the experiences of patients and medical personnel regarding the complexities of obstetric fistula as currently experienced in Sierra Leone. The study was a qualitative, institution-based study, with interviews of obstetric fistula patients and medical staff of the AWC in Freetown, Sierra Leone. The results will potentially be used

by public health advocates and policy makers as a platform to advance education and national policies and programs for the reduction and eventual elimination of obstetric fistula in Sierra Leone.

Research Questions

In this study, I investigated four key research questions in interviews with fistula patients admitted at the AWC. The questions were:

1. What are the experiences of OF as perceived by patients?
2. What are the experiences of OF as perceived by medical personnel attending obstetric fistula patients?
3. What do patients of OF perceive as barriers to medical care?
4. What do medical personnel attending OFpatients perceive as barriers to medical care?

Theoretical Framework

I used two models in this study. The first was the AAAQ model developed by the White Ribbon Alliance (Echoka et al., 2014). The second was the three delays model developed by Thaddeus and Maine (1994).

The AAAQ model describes a non-negotiable right to health care, guaranteed by assuring availability, accessibility, acceptability, and quality. The central piece of this concept remains the availability of adequate health infrastructure within a geographical zone that is physically and economically accessible, culturally acceptable, and of high medical quality (Pacaqnella et al., 2012). I designed this study to determine how failure to ensure the AAAQ of emergency obstetric care is associated with delays in health care

that can result in obstetric fistula.

The three delays model holds that delays in (a) individual decision-making to seek care, (b) identifying and getting to a health facility, and (c) obtaining adequate care after arriving at the facility (Echoka et al., 2014) are closely interwoven as barriers to care upon arrival at the health facility and influence subsequent decision-making to seek care. I used this theoretical framework to identify possible barriers to accessing adequate and quality care in all aspects of childbirth that have the potential to prevent long obstructed labor (Thaddeus and Maine, 1994). I used this model to give insight about the key actors in health decision-making, their demographics and factors that trigger their health decision-making, and barriers to accessing obstetric emergency care.

Nature of the Study

This was a facility-based, qualitative study in which I used a phenomenological approach to explore the experiences with and perceptions of obstetric fistula among 12 women suffering from obstetric fistula and eight medical personnel at the AWC where repair is done. Data was collected through open-ended individual in-depth interviews with the participants to generate descriptive data that illuminated the experience of fistula trauma and associated physical, emotional, and socio-economic experiences (see Sorrell & Redmond, 2008). The data was collected over a two month period until there was saturation of themes and no new ideas were generated.

The sample included both treated and untreated girls and women suffering from obstetric fistula who were at the AWC for treatment, along with eight of their attending medical personnel. Selection criteria for these girls and women included a diagnosis of

obstetric fistula and receipt of treatment at the AWC at the time of the study, regardless of age, ethnic background, regions of origin, socioeconomic background, or previous surgeries.

I conducted in-depth individual interviews with eight medical personnel, of which two were fistula repair surgeons and six were nurses at the AWC. The purpose of including these participants was to use their experiences and perceptions for up-to-date information about the current fistula situation, constraints faced, and things needed in order to improve fistula management. Medical personnel were also asked about the fistula patients' level of awareness about the causes of the condition, experiences, service availability, and costs of repairs.

I conducted this semi-structured interviews in Krio language, in a private place, using specially developed and pre-tested guides. The data were transcribed verbatim into English and analyzed using Nvivo 10th edition, which I interpreted and organized by identifying emerging themes that added to the rich description of the phenomenon, based on the participants' experiences and perceptions (see Hycner, 1985). Results reported in this study appeared as themes that emerged in participants' accounts of their experiences and perceptions. When developing these themes, I emphasized the AAAQ and three delays models.

Definitions

Acceptability Axis: A measure of whether healthcare services are acceptable to those populations served. It includes measures of cultural and psychological sensitivity, gender sensitivity, and medical ethics (PHR, 2010).

Accessibility Axis: A measure of whether healthcare services are accessible to all members of the population regardless of where they live. It includes sufficient transportation infrastructure, appropriate costs that are not prohibitive, and the extent of social bias against portions of the population (PHR, 2010).

Availability Axis: A measure of whether a particular location has a sufficient number of appropriate healthcare facilities, including sufficient numbers of competent staff, reliable water and electricity, appropriate facilities, and a sufficient supply of medications that are properly stored and current (PHR, 2010).

Obstetric Fistula: An injury that occurs during childbirth, generally as a result of prolonged labor. The child's head becomes lodged against the pelvic bone, which, if it stays that way long enough, can cause the vagina to burst, opening a hole between the vagina and the urinary tract, or between the vagina and the rectum, or both (UNPF, 2012).

Post-positivist Framework: Post-positivism is a philosophical approach to qualitative research based on a scientific approach. It recognizes that causes and effects are probabilities instead of certainties. The characteristics of a post-positivist framework include reductionism, logic, empirical research, and a priori theory (Creswell, 2012).

Quality of Care: The quality of care is an axis in the AAAQ framework. It refers to a measure of whether healthcare services provided are both medically appropriate and of good quality; this means that staff makes appropriate medical decisions, and services are provided in a competent and appropriate way (UNPF, 2012).

Three Delays Model: The basic tenets of this conceptual framework specify the

three main sources of human-caused obstetric care delays. The three delays are, first, a delay in making the decision to seek professional care; second, the delay in identifying and traveling to an appropriate healthcare facility; and third, the delay in obtaining adequate care after arriving at the facility (Echoka et al., 2014).

Medical Personnel: This term refers to nurses, physicians (fistula repair surgeons), physiotherapists, and counselors who have extensive experience working in gynecological health, particularly with women who suffer from obstetric fistula.

In this study, I used a convenience sample of participants. Inclusion criteria for participants included that obstetric fistula patients arriving at the AWC agreed to participate in this study, and that the medical staff who were mainly nurses, physicians (fistula repair surgeons), physiotherapists, and counselors attending to these fistula patients also agreed to participate given appropriate permissions from the patients. Convenience sampling was appropriate here as it occurred over a two-month period, which should have decreased the amount of bias associated with convenience sampling. I also used convenience sampling because in a preliminary investigation of demographic data, I noted that patients who use the AWC are from diverse backgrounds.

Assumptions

One assumption related to the qualitative approach to data collection is that the results of this study reflected a genuine causality (see Creswell, 2012). In order to mitigate the impact of such an assumption, it was important to use data triangulation approaches and compare responses from multiple participants and multiple types of participants (i.e., medical staff who were mainly nurses, physicians/fistula repair surgeons, and patients).

Also, the central assumptions of a post-positivist approach are that the social issues should be the objects of inquiry in social sciences, with the major concern that researchers should acknowledge and treat people as essentially human rather than as mere objects (Creswell, 2012). This is obvious since people or research participants (fistula patients and their healthcare givers) have the ability to think and experience the event under review. Unlike the post-positivist approach, positivistic research strategies cannot effectively deliver an understanding of these human dimensions.

I also assumed that the participants were in a rational frame of mind at the time of the interviews. Given that they would have arrived at the healthcare center in order to undergo a significant surgical procedure, it was important to ensure that they were well enough to provide quality responses and not excessively under the influence of medications or other issues.

Further, I assumed that the translations of the interviews from the Krio language were sufficiently accurate and appropriately reflected what the participants intended to communicate. The interviews were conducted in the Krio language, which was translated and culturally adapted into English. Such translation provides the potential for mistranslations, misunderstandings, or skewing of communications. Nuances are easily lost in translations between any two languages. Thus, the issue becomes one of ensuring that participants' responses translated into English properly reflect the meaning intended by the participants. The unstated assumption in this process was thus that all translations were accomplished successfully and accurately to reflect both the intent of the questions and the meaning of the responses. To help address this issue, the translations were

conducted by myself as native speaker of Krio who has also completed training in healthcare profession within the United States, thus giving a solid understanding of both languages and cultural nuances.

Scope and Delimitations

I collected the data for this study from participants admitted at the AWC over a specific 2-month period in 2016 for the purpose of receiving obstetric fistula correction surgery. I chose a convenience sample of participants on the basis of receiving the surgery as their reason for being at the center, willingness to participate in the study after its purpose and procedures were explained to them, and willingness to allow their medical staff (nurses, physicians [fistula repair surgeons] to respond to questions about their circumstances. No exclusions were made on the basis of age, social background, economic circumstances, or other demographic issues.

In this study, I addressed only the experiences and perceptions of the participants and their medical staff (nurses, physicians, fistula repair surgeons) with respect to perceived barriers to receiving medical care for their fistula, and with respect to their perceptions of the experiences of having a fistula. One goal was compare those perceptions between patients with the fistula and the medical staff attending those patients.

The AAAQ framework has four axes, availability, accessibility, acceptability, and quality of care. Of these, I focused primarily on availability and accessibility. Barriers to care can come about either because appropriate medical facilities are simply not available, or because the medical facilities that exist are not accessible to individuals who

need them. I explored both types of barriers in this study. The second set of research questions addressed both patient and medical staff perceptions regarding the experience of having an obstetric fistula. This more closely addressed issues related to the three delay model because those experiences derived from such delays.

This restriction on the specific axes I closely investigated in this study means that other axes of acceptability and quality of care received less focus and attention. Acceptability was addressed primarily through ethnographic or similar cultural comparisons. Quality of care was touched on to some degree in the study but was not my primary focus because the participants had all achieved the goal of receiving surgical care for their fistulas. Although some of the barriers to care presented in this study included issues of poor quality of care deriving from inadequate medical diagnosis or treatment at the time of patients' deliveries, my primary goals in the study were not to attack or indict the quality of medical care provided by the staff at AWC. I did not have access to prior medical records from other healthcare centers, and thus could not provide an objective and adequate understanding of any deficiencies in medical care prior to the visits indicated in this study.

Despite these assumptions, I believe that the results of this study may potentially contribute to better understanding the life experiences of women with obstetric fistulas and their perceptions of the quality of care that they received.

Limitations

Although not unusual for a qualitative study, there was a small sample size in the interview process. With a sample size of only a dozen women and girls with fistula and

eight medical personnel (six nurses and two physicians), generalizability and transferability of the results might be limited. Care was taken to choose participants on an objective basis, irrespective of ethnicity, region, age, economic status, or other considerations. The medical staff I interviewed included those who actually attended the participants in the study so that caregivers' perceptions and experiences could be compared to the patients' perceptions and experiences.

Another limitation derives from the nature of collecting qualitative interview data. As I have noted, language issues might have been a factor in that translations across languages are never fully accurate; the subtext sometimes lost in the process of translating to and from English. Thus, I used all means available to confirm the reliability of the translations to and from English to make sure that they reflected the actual meaning intended by all parties.

Researcher bias may have played an additional part in the limitations of this study in that the process of analysis of the qualitative data I collected required interpretation and value judgments. I made attempts to mitigate this limitation by having a second person double-check the analyses to ensure accuracy and consistency with the intentions of the participants. Reflexivity and bracketing were used to help further reduce interviewer and interpretation bias.

Significance

As a childbirth injury, obstetric fistula starts with the failure to recognize and treat pregnancy-related danger signs because most deliveries in poorer developing nations are done at home with unskilled birth attendants. In countries like Sierra Leone where this

epidemic is deeply rooted, the practice of early child marriage and pregnancy, female genital mutilation, grinding poverty, and lack of access to emergency obstetric care put women and girls at higher risk of obstetric fistula. In an event where family and community knowledge of the cause of the disease is unknown, but the physical evidence is present in the form of incontinence, victims are marginalized and discriminated against to the extent that they are often unable to fulfill their full potential and right to care (Warren & Mwangi, 2008; Zheng & Anderson, 2008). This health condition ruins the lives of already impoverished and powerless women, causing them to further lose self-esteem and dignity (Mselle et al., 2011). As Wall (2012) suggested, its incidence and prevalence are a living evidence of a failed maternal health care system.

Wall (2012a) further noted that obstetric fistula should be classified as a neglected tropical disease, but generally is not, in part because, unlike others in that category, it is not infectious, its treatment and cure are surgical rather than medical, it is not obviously fatal (although urinary and other infections that often result from chronic obstetric fistulas can indeed be fatal), and it is almost exclusively a condition of the poorest and least powerful people—impoverished women in developing countries who lack resources to ensure the safe birth of their children. The stigma these women experience because of this condition often destroys their lives in many ways–socially, psychologically, physically, and emotionally (Wall, 2012a). The significance of this disorder is that it reflects a medical, social, and political failure of nations to provide proper healthcare and treatment for its most vulnerable members.

Since this was the first study to explore experiences and perceptions of women

and girls who had obstetric fistula (and the medical personnel that worked with these women) and were undergoing corrective surgery in Sierra Leone, it adds substantially to the pool of knowledge on an issue that is given little attention, and for which there is limited public awareness. Shedding light on the predisposing factors, such as the practices of female genital mutilation and early marriage, and barriers to seeking care, the results will hopefully contribute to much-needed awareness about the condition and stimulate policy-makers to rise to the challenge of discouraging early child marriage and female genital mutilation, and by extending emergency obstetric services to rural communities where the disease is most prevalent.

Summary

This introduction included a description of the problem of obstetric fistula in developing nations such as those in sub-Saharan Africa. These holes in the vagina wall derive from long-term obstructed labor, often lasting for days. The result is nearly always a stillborn baby as well as catastrophic damage to the mother. The most commonly afflicted women are those who are extremely poor and who are primigravid adolescents whose bodies may not yet be fully mature and ready for pregnancy.

Sierra Leone experiences an epidemic of this debilitating, stigmatizing condition among its poorest women. Women who develop this condition are frequently shunned, lose their jobs, and experience a variety of issues including depression, post-traumatic syndrome, and ongoing series of urinary tract infections. Obstetric fistulas are both preventable with proper maternal care during delivery and treatable with surgeries to close the fistula and repair the damage.

The United Nations has estimated that as many as 50,000 to 130,000 cases occur annually in Africa, and as many as 3.5 million women are living with unrepaired obstetric fistulas. There is a lack of quality data about the victims of OF in Sierra Leone, yet that data is essential to understand how best to address this problem. Developing an understanding of how victims and medical personnel experience this problem can provide a better recognition of the risk factors for obstetric fistulas, can help identify those women who are most likely to experience this medical catastrophe, and can begin to change the cultural and social standards that contribute to the problem.

This study was a phenomenological investigation of the experiences of both victims of obstetric fistula and the medical personnel that attended those women when they came to a fistula surgical center in Freetown, Sierra Leone. The long-range purpose of this study was to assist in identifying policies and programs that could best help mothers avoid obstetric fistula and thus ultimately eradicate the disorder from Sierra Leone. The theoretical framework I used in this investigation combined the AAAQ framework, focusing specifically on its availability and accessibility axes, and the three delay model, which addressed the specific reasons why women in obstetric emergencies did not receive timely care. I conducted the study at the AWC in Freetown, Sierra Leone, interviewing women who arrived at the center for surgical repair of their fistulas. Data collected included direct interviews with such patients and interviews with the medical staff who attended those patients at this center.

The key significance of this study is that it might help public health advocates identify risk factors of the women who are most at risk for OF, and thus provide direction

to policymakers and program developers in how best to stem the epidemic of OF in Sierra Leone and eventually eliminate it from that country. The following chapter is a review of the literature on OF, focusing on sub-Saharan Africa in general and Sierra Leone specifically.

Chapter 2: Literature Review

Introduction

The primary purpose of this qualitative study was to explore the experience of OF from the perspective of the patient, while the secondary purpose was to explore the perspectives of medical staff treating fistula patients. The problem is that OFcauses significant health problems, and Sierra Leone has the highest rate of obstetric fistula in the world, impacting a good number of women and girls of childbearing age. As a result, my focus was on the physical, emotional, social, and economic impact of the OF. The absence of quality data to inform decision-making continues to serve as a barrier to creating an enabling environment for the prevention and care of fistulas in Sierra Leone. This problem is especially significant for Sierra Leone, which is one of the poorest nations with the highest maternal mortality rate in the world (UNPF, 2012).

This literature review is organized into major topics. First, I present a description of the search strategy used in this review. Next, I use major government and healthcare reports combined with research papers to explain the impact OF has on a woman's health, and the importance of addressing it. The following section includes a description of the conceptual frameworks I used in this study, the key elements of these frameworks, and examples of studies using them. Finally, I the summary section I summarize the results of this literature review's major themes, identify a gap in the literature, and offer a brief description of how my study bridges that gap.

Literature Search Strategy

I conducted this literature search using online academic databases of current

medical journals. Search terms included various combinations of *obstetric fistula, reproductive health, Africa,* and *obstetric health.* In addition to reviewing the papers identified by this initial topic search, I scrutinized the references cited in these papers to find other papers relevant to the topic of this study.

I also conducted additional searches of the websites of reputable healthcare organizations, such as the United UNPF's Obstetric Fistula Working Group and the WHO, to obtain further medical details about OF and the cultural and political issues involved in this condition. I conducted a final search of Google Scholar to identify any further papers relevant to this paper's topic. In all cases, I selected only papers published in peer-reviewed journals, or information from reputable professional and governmental sources, for inclusion in this literature review.

The literature search revealed relatively few papers published on this topic within the past 5 years. For that reason, I expanded the search to include papers published in the past 10 years. As a result, articles and seminal publications selected for inclusion in this literature review were published in 2004 or later.

The Facts of Obstetric Fistula

Obstetric fistula occurs when there is prolonged, obstructed labor during childbirth when timely and effective medical intervention does not occur (UNPF, 2014). Women in poor countries are 100 times more likely to develop an obstetric fistula than women in developed countries (Wall, 2006). This contributes to the fact that 99% of maternal deaths due to childbirth occur in these poor countries (Wall, 2006). Such maternal deaths are possible, particularly if victims of fistula live in an area that is devoid

of access to information and services and is characterized by poor hygiene and infection control. Under such circumstances, the lives and well-being of victims are impacted as their condition leads to ulcerations and future infections of the kidney, nerve damage, depression, suicidal ideation, and ultimately death (Wall, 2006). Equally as important, women who experience OF and who do not die suffer long-term crippling injuries that ostracize them, reduce their financial and social status, and often leave them in dire personal straits (Wall, 2006).

In a recent review of the literature on obstetric fistula, Zheng and Anderson (2009) reported that between 82% and 100% of cases exhibited an etiology of prolonged labor. In such prolonged labor, typically the pressure of the baby's head against the pelvic bone opens a hole between the vagina and the bladder and/or the rectum (UNPF, 2013). This almost always results in the death of the child and leaves the mother with incontinence, stigmatizing her and leaving her isolated from her communities, often abandoned by husband and family (UNPF, 2013). The isolation also often makes these women unable to find work and leaves them even more deeply impoverished (UNPF, 2013).

Women with obstetric fistula who undergo surgical repair procedures can anticipate successful results. Treatment of the condition costs about $300 per person, including surgery, post-operative care, and rehabilitation support, and has a success rate greater than 90% (UNPF, 2012). Browning and Menber (2008) found that 6 months after such surgical repair, incontinence was largely eliminated as a problem and the patients reported significantly improved quality of life. Women were also able to resume sexual

intercourse after treatment, and this was largely reported to be without pain (Browning &Menber, 2008). These improvements in their physical condition allowed many to be reintegrated into society. An earlier study had shown that fistulas that involved the urethra, the woman having a small bladder, the presence of vaginal scarring, and a large diameter fistula were all characteristics of women who had less successful relief from incontinence after surgical repair of the fistula (Browning, 2006).

Although most cases of obstetric fistula can be both prevented, as with a cesarean section, and treated, generally with surgical repair of the hole, the condition occurs most often in women who are marginalized and impoverished, especially when there are few or no medical facilities in their area (UNPF, 2014). One of the major side effects of obstetric fistula is that of urinary incontinence, which can stigmatize women with this condition, make them unable to find or keep husbands, further marginalizing them in their culture (UNPF, 2014).

In 2003 the UNPF started the Campaign to End Fistula with three strategies: to prevent fistula from occurring, to treat those women who are affected by it, and to support the women after they undergo surgical repair of the fistula (UNPF, 2014). The U.N. estimates that there are between 50,000 and 100,000 new cases of obstetric fistula every year, and at least 2 to 3.5 million women have this condition, even though it is both preventable and treatable (UNPF, 2012).

Conceptual Framework

Researchers have made several attempts to create a framework for understanding obstetric fistula. One framework, generated by Wall (2012), addresses four levels of

determinants–remote determinants, intermediate determinants, and acute clinical determinants–relating them all to clinical outcomes. For example, remote determinants consist of issues separate from the actual pregnancy. Wall identified these as issues relating to (a) the woman's status in the community (items such as education, occupation, income, etc.); (b) the family's status in the community (items such as the amount of land the family has, the family income, occupation, social networks and political connections, etc.); and (c) the community's status (items such as the aggregate wealth of the community, transportation infrastructure, doctor availability, political influence, healthcare resources, etc.). Intermediate determinants in Wall's framework include items in four specific areas: the woman's health status, her reproductive status, her access to health care, and her use of healthcare resources available to her. For example, health status includes nutrition, weight, infections, parasites, and any chronic conditions such as hypertension or diabetes. Reproductive status includes age, marital status, and prior reproductive history. Access to health care not only includes the availability of facilities either in her community or nearby, but also the services that are available there, the quality of care they can provide, and the information the woman may have about those healthcare services (Wall, 2012).

As for outcomes, Wall (2012) identifies three key possibilities: maternal death, resolution of the obstructive labor prior to the development of the fistula (i.e., via cesarean section), or the development of the fistula (Wall, 2012). This framework, though useful as an abstract epidemiological schema, was inadequate for the purposes of this study because it focuses almost exclusively on how the various determinants impact the

clinical condition.

There are, however, two more useful frameworks, which I used in this study. The first is the AAAQ model for assessing national healthcare, which considers the four axes of availability, accessibility, acceptability, and quality of care (Echoka et al., 2014). The other is the three delays model (Thaddeus & Maine, 1994), which is based on the fact that 75% of maternal deaths have human obstetric causes, which is the case with obstetric fistula. I used this model to identify possible barriers to accessing adequate and quality care in all aspects of childbirth that have the potential to prevent long obstructed labor. In the following subsections, I discuss each of these two models.

Three Delays Model

The basic tenets of this model include delays in individual decision-making to seek care, in identifying and getting to a health facility, and in obtaining adequate care after arriving at the facility (Thaddeus & Maine, 1994). Theses phases of delay are closely interwoven as barriers to care, poor care experiences upon arrival at the health facility, and influences on subsequent decision-making to seek care. Because women of reproductive age often lack decision-making power in regards to health in poor settings, the use of the three delays model gives insight into the key actors in health decision-making, patient demographics and factors that triggers their health decision-making, and barriers to accessing obstetric emergency care. In the following studies, researchers have demonstrated how they have used the three delays model.

Echoka et al. (2014) conducted a qualitative study of women who experienced near misses in obstetric care in the Malindi District in Kenya. The goal of the study was

to determine if their dangerous obstetric experiences were related to the issues in the three delays model. The interviews identified whether the mother was aware of signs of problems with the pregnancy, her delivery experience, what type of prenatal care she experienced, the rationale for her choice of healthcare facility, how far she had to go to that facility and how she got there, and her overall experience of childbirth. The women were also asked how they perceived the quality of care they received. The results showed that women experienced a combination of delays in seeking obstetric services. For example, despite having generally good knowledge of danger signs, they often delayed seeking help. They also often did not identify in advance a healthcare facility that could help them. Even when the decision to seek care was made in a timely fashion, the women often experienced delays in arriving at the care facilities because of lack of available transportation or long distances and poor quality roads. Echoka et al. acknowledged that multiple examples of the third delay–lack of timely care once a woman arrived at the hospital–did exist, but they concluded that the first two delays–delay in the decision to seek healthcare, and delay in the travel time to the healthcare facility–held greater weight for the women in their study.

Waiswa et al. (2010) used the three delays model to understand the reasons for neonatal deaths in Eastern Uganda. The researchers investigated 64 neonatal deaths occurring at a variety of locations including hospitals, private clinics, and in no healthcare facility (i.e., home births). Just over half of the infants died in no healthcare facility, about half died within one day of birth, and 78% died within the first week of birth. As with Echoka et al.'s (2014) study, major factors in infant deaths included (in

decreasing order of impact): delay in recognizing problems and seeking care (50%), delay in receiving care at a health facility (30%), and delay arising from the time needed to arrive at the healthcare facility (20%). Unlike Echoka et al.'s conclusions in Kenya, healthcare facilities in Uganda were significant contributors to neonatal deaths by the delay patients experienced in receiving care.

AAAQ Framework

The AAAQ model uses four specific aspects of healthcare: availability, accessibility, acceptability, and quality of care. These four qualities have been used to determine whether national healthcare systems meet human rights standards. Specifically, PHR (2010) defines *availability* as whether a nation has adequate numbers of healthcare facilities, goods, and services. This includes having a sufficient number of hospitals, clinics, healthcare workers, medications, preventative medicine programs, and basic hygiene needs such as clean drinking water and sanitation services (PHR, 2010). *Accessibility* is defined as making healthcare services available to everyone in the population regardless of location, i.e., urban or rural, and economic status, including the right to receive health information (PHR, 2010). *Acceptability* means that the healthcare provided must respect local cultural traditions, be gender sensitive, and be medically ethical; this includes ensuring that medical procedures are adequately and understandably explained to the patients and their families (PHR, 2010). Finally, healthcare should be both medically appropriate and backed by good *quality of care*, which includes treating people respectfully (PHR. 2010).

This AAAQ framework has provided the explicit basis of a number of studies of

healthcare systems in sub-Saharan Africa. Some of these studies, in the U.S. and other developed countries, focus primarily on two of the four elements of this model, accessibility and quality of care. For example, van der Ries and Savage (2007) focused almost exclusively on issues of providing quality care at an economically accessible price. This study, although acknowledging the other axes of acceptability and availability, primarily focused on whether economic issues made healthcare inaccessible and whether the result in all cases was high quality of care. Interestingly, van der Ries and Savage did not attend much to the issue of treating patients respectfully as part of quality of care; their focus was almost exclusively on providing successful medical procedures and treatments.

In contrast, a similarly intentioned study by Hsia et al. (2012) considered availability and quality of care in five nations in sub-Saharan Africa, looking primarily at availability of emergency and surgical care in that region. The nations included in this study were Ghana, Kenya, Rwanda, Tanzania, and Uganda. The specific variables used in this study considered availability of basic infrastructure, proper equipment, storage of medications, ability to control infections, education and training of staff members, and quality control procedures {Hsia et al., 2012). These researchers found dismal results in considering healthcare accessibility and quality of care across the five nations, including a lack of reliable running water and electricity, inability to provide 24-hour care, expired medications, poor availability of infection control equipment and supplies, and poor disposal of hazardous waste. Most nations in the survey had inadequate personnel training or supervision in place (Hsia et al., 2012). With such massive lacks in

availability, which certainly spills over into a lack of quality care, the axes of acceptability and accessibility were submerged in this study, though differences in rural and urban accessibility were noted.

An earlier study of obstetric services in northern Tanzania noted that availability and quality of care for services were poor, averaging only 36% of health facilities, with nearly all of that concentrated in urban areas (Olsen, Ndeki, & Norheim, 2005). This study used a 1997 framework from the United Nations to measure the adequacy of availability and quality of obstetric care. The questions addressed in this study included:

- Are there enough facilities providing emergency obstetric services?
- Are these facilities distributed well across the region?
- Do enough women use these facilities, with levels below 15% being considered inadequate?
- Are the right women, those with expected complications, using the facilities, with 100% of those expecting complications being considered inadequate?
- Are enough critical services (i.e., cesarean sections) provided, with a range of 5% to 15% being considered adequate?
- Is the overall quality of service adequate, as measured by direct obstetric deaths in the facility, with less than 1% being considered adequate?

As with the two prior studies, the focus in Olsen, Ndeki, & Norheim (2005) is on absolute numbers of medical facilities and equipment and quantifiable medical outcomes. Data on less quantifiable areas such as cultural sensitivity and proper treatment were not collected.

One final example of how the AAAQ framework has been implemented in prior studies is the 2009 study by Parkhurst and Sengooba in rural Uganda. Once again, the study was based on quantifiable measures and thus focused on issues such as the percent of babies born in healthcare facilities, the proportion of local women using the centers, and similar measures of the use level of such facilities (Parkhurst & Sengooba, 2009). Again, the focus was almost exclusively on the availability axis of AAAQ and on quantifiable measures, e.g., number of births and number of obstetric deaths.

Rationale for Use of AAAQ and Three Delays Frameworks

The use of the AAAQ framework is not widely represented in the literature, probably in part because the notion of acceptability of medical procedures to the local culture is very difficult to quantify. This is reinforced by quality of care issues that include treating patients respectfully. Such measures often are ignored in studies of sub-Saharan Africa. For a qualitative study such as the current research, however, the use of a more encompassing framework that includes such issues provides greater depth of understanding. Given the reality that women of reproductive age lack health-seeking decision-making power, the use of the Three Delay model adds further insight about the key actors in health decision-making, their demographics, other factors that trigger their health decision-making, and barriers to accessing obstetric emergency care. It is for this reason that combining the AAAQ framework with the Three Delays model is expected to provide a solid conceptual framework for understanding the problems of obstetric fistula in Sierra Leone.

Applying the AAAQ Framework to Studies on Obstetric Fistula

This section of the literature review focuses on studies that consider obstetric fistula in sub-Saharan Africa and are discussed organized by the four axes of the AAAQ model: Availability, accessibility, acceptability, and quality of care. As noted in the previous section, these axes are not equally represented in the literature. While not all the studies identified in this review explicitly use the AAAQ framework, all of them address one or more of the four axes in that model.

The availability axis. Women who have obstetric fistulas generally require surgical treatment to correct the injury (Ramsey &Pinel, 2007). Those who do not require surgery often require catheterization for the short term to allow the fistula to close and heal (Ramsey & Pinel, 2007). In either case, the ultimate need is for an available team of surgeons and support staff for surgery or medically safe methods of catheterization. To prevent the development of fistulas in the first place requires the availability of high quality cesarean sections to avoid excessively long labors (Ramsey & Pinel, 2007). Without adequate surgical care and post-operative care the women may experience worse problems than the fistula due to infections and other complications (Ramsey & Pinel, 2007). Not all the problems are strictly physical, however. Other services must also be made available to at-risk obstetrics patients, including psychological and counseling services, and even physiotherapy as needed to assist the women (Ramsey & Pinel, 2007). All these issues speak to a lack of available, high-quality medical services to women in developing countries, particularly those in sub-Saharan Africa.

Availability of care for obstetric fistula patients is not a simple issue. This is

because proper care of these patients is often not a one-shot, quick surgical fix (Maulet, Keita & Macq, 2013). In an 18-month cohort follow-up study conducted of fistula repair patients in Niger, Maulet et al. discovered that a multitude of delays dogged these patients even after they made the decision to seek medical repair of their obstetric fistula. In this study, two of the three delays in the Three Delays model were quantified. The delay between the time of the occurrence of the fistula and the time they first appeared at the fistula repair center was a median of just over 4 years (Maulet et al., 2013). Transportation delays were not explicitly measured in this study. The other delay was the time between the participants' arrival at the center and the time it took them to declare that they were either healed from their fistula or "incurable" according to the patients' own determination (Maulet et al., 2013). These patients in Niger faced delays, often on the order of weeks, after they first arrived at the repair healthcare facility before they could have surgery. This was due to an insufficient number of qualified and available surgeons and facilities to do the fistula surgeries (Maulet et al., 2013). Thus, the lack of available healthcare resources directly contributed to this third delay in the Three Delay model. The median time these participants spent at the healthcare center was seven months, and almost 10% of the participants in the study were at the healthcare center for the entire 18-month duration of the study (Maulet et al., 2013).

Since incontinence is often not resolved after a single fistula surgery, alternative management alternatives have to be considered. Goh and Browning (2005) acknowledged the lack of total success in surgeries by conducting a pilot study on the use of urethral plugs to assist in urine control. Goh (2005) found that such plugs effectively

controlled incontinence and improved overall bladder function. Unfortunately, the mechanism for achieving plug usage in cash-strapped countries involves reusing "disposable" items. This raises serious issues with respect to infections since the urethra connects directly to the bladder and thus to other internal organs (Goh, 2005). Furthermore, equipment and resources needed for urodynamics studies to determine causes of incontinence are typically not available in developing countries (Goh, 2005). While effective in the short term in this study, the usefulness of such plugs long term was not studied and may be questionable.

Furthermore, although surgeons generally claimed to use antibiotics before, during, and after surgery, the reality was that extended spectrum antibiotics are often unavailable in African hospitals, particularly those in West Africa where multi-drug resistant organisms have been found to be prevalent (Arrowsmith et al., 2010). The lack of availability of urodynamics facilities and personnel also inhibited proper diagnosis and treatment for post-surgical incontinence (Arrowsmith et al., 2010).

Overall, the availability of treatment for obstetric fistula is an important issue in African underdeveloped nations. Leung and Chung (2009) reported that approximately 9000 new cases of obstetric fistula occur each year, but only about 1200 of them receive any treatment. This occurs for a complex of reasons including lack of education, poverty, lack of availability of trained personnel, medical centers, and supplies, and lack of governmental support due to the low status of women and the classification of the problem as not being an emergency situation (Leung & Chung, 2009). Only a few hospitals in the poorest countries where fistulas are most prevalent are capable of

providing the surgeries needed to close the fistulas (Leung & Chung, 2009). The lack of available transportation is a huge problem in these cases. Leung and Chung (2009) note that more than 80% of the patients at the Addis Ababa Fistula Hospital in Ethiopia had to travel at least 700 km to get there, contributing to delay due to travel issues in the Three Delays model. The lack of availability of medical care within easy reach of the women who need it is thus an important reason behind the growing problem of obstetric fistulas in poorer African nations (Leung & Chung, 2009).

The accessibility axis. In many parts of the world, including many parts of sub-Saharan Africa, it is culturally accepted to perform female genital mutilation (FGM) in which all or part of the female genitals are removed. Jina and Thomas (2013) report that this practice has numerous reproductive health experiences for women, including being a causal agent for recto-vaginal fistulas. This practice also doubles maternal deaths in childbirth because it makes labor more difficult, and is compounded when armed conflicts or natural disasters disrupt accessibility to healthcare services, especially if the experience of being raped occurs, which often stigmatizes women and further limits their access to healthcare. This means they are often unable to marry and any child born as a result is equally stigmatized (Jina& Thomas, 2013).

Thus, in areas where women are either forced to undergo FGM or where they are subject to rape as a result of warfare or natural disasters, the incidence of obstetric fistula is likely to increase due to inadequate healthcare accessibility. With that said, the evidence regarding FGM as a causative factor for obstetric fistula is not clear-cut. A 2010 study of women with obstetric fistula found few significant differences between those

who had undergone genital mutilation and those who had not (Browning, Allsworth, & Wall, 2010). Although this study found some statistical significance in the need for catheterization during fistula repair between the two groups, the authors claimed this was not a significant clinical difference, nor did surgical repair outcomes differ significantly between the two groups (Browning et al., 2010). The authors concluded that rather than genital mutilation being a cause of obstetric fistula, it is instead a marker for other societal conditions that produce a higher likelihood of obstructive fistula. Browning et al. suggested that primary causes of obstetric fistulas included low socio-economic status of women, early marriage, and pregnancies before pelvic growth is completed, limited or no access to contraceptives, lack of education of women, little political power for women, poor transportation networks, and a lack of adequate and accessible healthcare facilities. Thus, accessibility to healthcare was cited by Browning et al. as a more likely cause of obstetric fistula than the genital mutilation itself.

In Sierra Leone, one effort to improve overall accessibility to medical care for obstetric cases has been the provision of special motorbikes used as ambulances to transport women to medical centers (Bhopal, Halpin, & Gerein, 2012). The motorbikes involved were specially designed to travel over the difficult roads in that nation and to provide relatively easy transport to health centers when needed. Bhopal et al. (2012) reported that training traditional birth attendants has increased awareness of the service and improved the overall accessibility of healthcare to women with obstetric emergencies.

Accessibility was also shown to be a problem in Zambia where a study of the

characteristics of women with obstructive fistula at a southern Zambian healthcare facility identified specific characteristics that were more likely to presage development of the problem (Holme, Breen & MacArthur, 2007). In addition to finding that women with obstructed labor were likely to be shorter than normal, most of those developing obstetric fistulas experienced prolonged labor of at least two days before seeking medical care. Holme et al. (2007) also found that most cases came from parts of Zambia where the transportation network is poor. Surprisingly, Holme et al. found that relatively low numbers of the Zambian women had been divorced by their husbands, an occurrence that often happens as a direct result of the incontinence resulting from obstructive fistulas.

A further complication in providing available medical care for women in an obstetric crisis such as prolonged labor was the co-occurrence of Ebola in Sierra Leone and other West African nations. Black (2015) noted that there was an overlap in diagnostic criteria that means that a woman in labor might initially be perceived as a potential Ebola carrier. The diagnostic tests to determine if she was free of Ebola could take 24 hours or more, during which time she might well receive no treatment at all, in spite of the life-threatening crisis she was undergoing (Black, 2015). This is particularly true because childbirth is a specialty with the extremely high likelihood of exposure to blood and other fluids which were the primary transmission agents for Ebola (Black, 2015). The ethics of withholding medical care from a patient in a potentially life-threatening circumstance simply because she *might* be carrying Ebola is a significant dilemma for healthcare workers in the field (Black, 2015). It is even more challenging when the current recommendations state that personal protection equipment (PPE) should

be worn for a maximum of one hour at a time, and their use during any type of surgical procedure is problematic at best because of limits in vision and fine motor control in those suits (Black, 2015). Even doing preemptive testing of all patients for Ebola was not a useful strategy because while in the incubation stage, the tests had a high false-negative result (Black, 2015). The fear of Ebola also caused women avoid seeking medical help until they were truly in a crisis mode, making it even more difficult to distinguish obstetric crises from Ebola cases (Black, 2015). Sierra Leone's ongoing problems with Ebola at the time of the research exacerbated the issues of the Three Delays for women experiencing obstetric crises in that nation (Black, 2015).

Further support for the importance of accessibility with respect to obstetric fistula prevention and care derives from another 2007 study by Meyer et al. in Niger. Here again, the authors cited accessibility to emergency obstetric care as an important causative factor in the development of obstetric fistulas. Furthermore, Meyer et al. found that accessibility in terms of disparities between the very poor and the rest of the population also contributed to the development of obstetric fistulas.

The acceptability axis. Cultural considerations provide critical importance in prevention of obstetric fistulas. Muleta et al. (2007) found in a study in rural Ethiopia that cultural norms played a substantive role in making women vulnerable to fistula development. Specific cultural factors that Muleta et al. identified included the very young age of marriage for girls and correspondingly early first births as a correlate to development of fistulas. These young girls were in labor from three to eight days, with such extreme labor times generating a higher likelihood of fistula development. Muleta et

al. urged cultural changes focusing on increasing the age of marriage and first pregnancies as an important key to reducing the number of fistula patients in rural Ethiopia. Over the long run, Muleta et al. emphasized that improving the financial condition and status of women in Africa was a necessary precursor to preventing fistulas in future.

Zheng and Anderson (2009) surveyed available literature on obstetric fistula in a number of African nations (Ethiopia, Nigeria, Ghana, Niger, Zambia, Kenya, Tanzania, and Uganda). Cultural traditions were found to be contributing factors in virtually all these. For example, in Ethiopian studies, between 44% and 52% of the women who developed obstetric fistulas were deserted by their husbands, leaving them isolated and socially disadvantaged. Generally speaking, well over 90% of the women across all these nations were married before the age of 18, and many studies showed an average age at marriage of approximately 15.5 years. Most studies also showed these women tended to be very poor and/or illiterate (Zheng & Anderson, 2009). One issue that Zheng and Anderson noted is that few of the studies are community-based rather than clinic-based or hospital-based. Community-based studies suffered badly from a lack of demographic and population data (Zheng & Anderson, 2009). Such characteristics were similar to those found in an earlier study by Wall et al. (2004) in Nigeria. That study had identified characteristics of women likely to experience obstetric fistula based on women who came to a hospital for surgical repair as those who were small and short, and who were married before the age of 16, had a stillborn child during their pregnancy and developed the fistula in their first pregnancy (Wall et al., 2004).

Shefrin (2009) approached the problem of prevention of obstetric fistulas by determining a set of preventive strategies that could assist in reducing the number of cases. Shefrin (2009) specifically addressed the problem of obstetric fistulas in Ethiopia, but his recommendations bear weight for other developing African nations. Some of these require significant cultural changes to enable better education of women and reduction of cultural practices such as very early marriage and childbirth (Shefrin, 2009). An additional key strategy proposed was to add more fistula surgical centers farther into rural areas, making medical care more accessible and available to women (Shefrin, 2009). However, this also addresses the importance of making the medical care more acceptable to them by making the staff and center familiar and comfortable –part of the community rather than strange and remote in the urban areas. Shefrin (2009) noted that 94% of births in Ethiopia have no medical personnel in attendance, so another key strategy was to train midwives who can assist local women with their prenatal and obstetric care. Again, this is a suggestion that addresses the availability and accessibility axes of the AAAQ framework, but it also addresses the issue of acceptability, since the midwives trained would be members of the local community and thus familiar and comfortable to the women who need their care.

Roush (2009) addressed the actual knowledge of how obstetric fistula impacts women's socio-economic status by reviewing the literature addressing these acceptability issues. Roush found that the literature was seriously lacking in in-depth assessments of these factors, with most studies focused almost exclusively on surgical correction statistics and surgical considerations. For example, studies such as that by Nardos,

Browning and Chen (2009) focus on surgical risk factors that can predict which women are at risk for having their repaired fistula fail. While clearly an important topic for doctors and medical staff, it does not directly address the most important issues to the woman involved. For example, with constant incontinence, and in a location where access to clean, potable water is scarce, techniques for remaining clean, odor-free, and uninfected are paramount (Roush, 2009). Constant irritation from the urine can lead to skin breakdown, infections, and pain – issues that further isolate and impair the women (Roush, 2009). Roush emphasized the importance of providing a local support network to help them decrease isolation factors, and to provide opportunities for economic stability via whatever community resources are available.

Not all of the delays in getting patients to the point where they can return to their prior lives after fistula repair are necessarily due to healthcare delays in treatment or delays in seeking care. In spite of earlier studies, such as that by Ahmed and Holtz (2007) that consistently report that surgeries are generally successful (clinically) and allowed women to reintegrate socially after the repair, Maulet et al. (2013) in their 18-month cohort follow-up study found that many women required multiple surgeries to correct their fistulas. Instead of the more commonly reported before/after presumption that a single quick surgery corrected the problems the women faced, women in this study in Niger often needed multiple surgeries spaced over weeks or months. The surprising results of this study include the high proportion of women who are not healed by their fistula surgery, and who still experience incontinence. This study found that more than half (69 of 109) women were still incontinent – either urinary incontinence (65) or

urinary and fecal incontinence (4) after the 18-months of the follow-up study (Maulet et al., 2013). These women had to undergo the trauma, stigmatization, and delays in treatment over and over again as they strove for a true cure for their condition. Maulet et al. noted the importance of providing women with obstetric fistulas a long-term care plan that includes follow-up to determine the functional success (as opposed to clinical success) of their surgeries.

The impact the obstetric fistula has on the lives of the women also continued to evolve due to the long duration of the symptoms and recurring surgeries many needed (Maulet et al., 2013). This means that the issues of acceptability of care are more crucial than would be implied by the studies that simply count the number of surgeries that initially appear clinically successful. In particular, during the course of Maulet et al.'s 18-month follow-up study in Niger, the marital status of the women often changed, second wives often had to be accepted, taking the place of the woman with the fistula, and economic stresses on the woman and her family increased as a result of the long-term care she needed.

The socially unacceptable aspects of their condition lingered long after their first surgeries. Maulet et al. concluded that it was important to look beyond a quick-fix surgery and provide women with social, economic, and especially long-term care and follow-up to ensure they return to their lives successfully. The authors also noted a dearth of studies that provided the long-term follow-up of obstetric fistula patients, and strongly urged a less quantitative-only approach to the subject, suggesting more qualitative and mixed-methods studies and long-term longitudinal studies to better understand the impact

of obstetric fistulas on the lives of the women experiencing them.

The quality of care axis. As noted earlier, quality of care includes not only the degree of expertise of the medical staff caring for patients, but also the degree to which patients are treated respectfully and their impression of the quality of care they receive. In some cases the quality of care that obstetric fistula patients receive even when they make a decision to seek medical help and travel to the medical center, whether near or far, may not be particularly high.

A study in Malawi in southeastern Africa used a grounded theoretical approach to investigate the causes of maternal deaths (Thorsen, Sundby, & Malata, 2012). Their interviews identified a number of causes, including delays due to the need to travel long distances to a healthcare center, delays in recognizing help was needed, and delay in receiving prompt care at the healthcare facility (Thorsen et al., 2012). In this case, the most common delay was delay in receiving care once at the hospital due to a variety of systemic problems combined with lack of resources. Thorsen et al. concluded that mismanagement and inadequate healthcare facilities and staff were key reasons these mothers died. The quality of care for the women in this study was below acceptable standards (Thorsen et al., 2012).

One of the difficulties in establishing quality care for fistula patients is that there are no clearly identified best practices for these patients. Arrowsmith, Ruminjo and Landry (2010) surveyed surgeons who regularly performed fistula surgery in Asia and Africa to determine what their standards of practice were for these cases. Although responses conceded that the type of surgical repair affected the overall outcome for the

patients, these authors concluded that insufficient studies have been done to understand what specific types of surgical interventions are most effective. They also noted that there is no standard treatment for post-surgical incontinence, and a lack of data to determine best practices for management of that condition. Even basic issues such as how to manage post-surgical catheters had little consensus, with some surgeons leaving in catheters for only five days after surgery and others for a full six weeks. Arrowsmith et al. found no clinical evidence for either end of that catheterization duration spectrum.

Other issues of quality of care include that of presuming the obvious in determining the cause for the urinary incontinence symptoms women experience with obstetric fistulas. Specifically, Goh et al. (2013) have also noted that post-surgical management of urinary symptoms is often neglected. These authors noted that medical staff rarely looks further than the fistula itself to explain the incontinence problems, and follow-up for many patients is very difficult, particularly in rural areas. Some surgeons use unconventional and unproven surgical techniques in their attempts to repair the fistulas in their patients. Even when the fistula is successfully closed, women often still experience incontinence; Goh et al. placed the estimated number of women with "successful" fistula closure surgeries who still experience urinary issues at about 25%. In their analysis of post-surgical women with obstructive fistulas, a significant issue was the poor state of the medical records regarding the surgery (or surgeries), and the specific techniques used for closure in those surgeries. These data were insufficient to provide conclusive answers to the cause of these women's continuing incontinence. However, Goh et al. found that overactive muscles in the bladder walls may be a significant

contributor to incontinence, and that treatment by surgical means would therefore probably not represent optimal medical care.

To provide true quality healthcare, it is important to address more than the surgical/medical issues involved in obstetric fistulas. Heller (2014) conducted an anthropological study of women in Niger who experienced obstetric fistulas. The women had been told nothing about the potential experiences of prolonged labor, including that they might become incontinent, nor that they might not be able to walk due to nerve damage as a result of the extended labor. Heller reported the typical response to these women when they awakened from the cesarean that ended their labor – often labor lasting up to a week – was that they were either told nothing about the incontinence they would experience, and should just go home, or they are told it was "normal," or that it would go away by itself (Heller, 2014).

In Niger there is a 40-day cleansing ritual after childbirth or labor, and most women do not seek help until after that period ends. Most often, Heller states, when they go to clinics or a hospital, they are told nothing about what might be wrong to cause their ongoing incontinence. These women have to pay the clinics for this unhelpful advice, receiving at most, simply a box of pills, with no explanation of what they are intended to do for them. Heller claims that women may go through a dozen or more clinics without ever getting a diagnosis, and each such visit is an economic burden to an impoverished family. When they finally reach a fistula clinic, they have papers they can't read, in languages they don't know, and have never been told the word "fistula" or any local language translation of that word. The result is that the women are not only ostracized

because of their symptoms, they are persistently isolated even from other women with the same complaints (Heller, 2014).

When Heller observed interactions between patients and the massively overworked clinicians, she found the most common response to any request for more information to be one of shrugging aside their need to understand what was happening to their bodies, a refusal to take the time to explain their condition, the type of treatment that might help them, or the experiences and expected side effects of that treatment (Heller, 2014). In other words, the quality of care women received in Niger for this problem was inadequate at best and dehumanizing at worst (Heller, 2014). Even worse, often women aren't even informed of what the surgeon did to them – including, in some cases of emergency obstetric surgery, removal of the uterus (Heller, 2014). Women are not taught strategies they can use to cope with ongoing incontinence, nor are they provided with urethral plugs or other needed resources to cope (Heller, 2014).

Part of the lack of communication with the fistula patients may be due to their impoverished state, Heller (2014) asserted. Prior anthropological studies in Turkey had found that the higher the socioeconomic status of the patient, the more likely the doctors were to take time to explain medical conditions (Heller, 2014; Buken, 2003). Heller stated that non-disclosure is also a consideration in a society with highly unequal power distribution between the sexes.

Storeng et al. (2010) conducted an in-depth follow-up series of interviews over a one-year period of women who survived a "near-miss" pregnancy with obstetric fistulas. This study is one of the few that look beyond the basic statistic of whether the mother

survived both pregnancy and surgical repair of the fistula or other life-threatening obstetric events. Conducted in Burkina Faso, one of the most impoverished nations in all of Africa, the ethnographic survey compared those women with such near-miss obstetric events occurring during pregnancy through six weeks after birth with women who had uncomplicated pregnancies and childbirths (Storeng et al., 2010).

While not all the obstetric events included in this study were due to obstetric fistulas, Storeng et al. (2010) provides an important insight into how such medical emergencies impact the lives of women. This in-depth study found that such obstetric emergencies massively disrupted the lives of the women and their families. First, the economic cost of the medical care was a catastrophic impact on the families of the women (Storeng et al., 2010). In addition, while their bodies may have been healed from a medical standpoint, loss of body integrity involved much more than simple medical healing. Women often experienced long-term physical issues such as loss of sense of control over their bodies, feelings of loss and weakness, inability to resume their usual productive family activities, and even their ability to become pregnant again (Storeng et al., 2010). The emotional context of those impacts also had an important impact, beginning with the stress and confusion involved in simply getting to the hospital to receive the needed care (Storeng et al., 2010).

The impacts Storeng et al. uncovered did not end there, however, with some women expressing feelings of being traumatized and feeling that the care they received at the healthcare facility was both poorly explained to them and information was imparted in a demeaning, denigrating manner. In some cases, the information was given to them in

languages the women did not understand and in one case cited by Storeng et al., the woman reported being physically hurt and "mutilated" genitally. The women generally associated loss of physical strength with a shortening of their lives. In another specific case, a woman with hypertension after her childbirth and treatment was only able to receive necessary medication to control it every two weeks out of four, meaning that she was forced to be dependent on others half the time because of the dizziness from her hypertension (Storeng et al. 2010).

If the emotional impact of obstetric fistula on women who needed emergency obstetrical care is severe, the economic impact is even more far-reaching. Storeng at al (2010) found that, while these women may have set money aside for general childbirth expenses and supplies, the costs associated with emergency care can devastate family finances, and often, attempts to mitigate the economic impact result in medical and physical issues being ignored or deferred. With all these complications, the women in this study experienced one more, which was the disruption of their social status. Many husbands were punitive, blaming the disruptions on their wives, and often abandoning the women either while still in the hospital or shortly thereafter. This was particularly the case when the child did not survive and there were no other children in the family; then the woman's status and position in the family were threatened, with husbands sometimes taking a second, potentially more fertile wife even when the injured wife was not formally divorced. This was more complicated when medical advice after the surgical correction was to avoid pregnancy for two to three years, while husbands were reluctant to make use of contraceptives (Storeng et al., 2010).

This type of in-depth ethnographic information goes far beyond the usual question of "did the husband divorce the woman after the obstetric fistula?" As can be seen in the Storeng et al. research, merely retaining the status of being "married" does not fully express the types of social demotion that women undergoing this type of obstetric emergency must endure. Studies such as this emphasize the importance of doing more than quantitative research on this problem. Qualitative research is needed to fully understand the scope of the issues involved.

Another study in Ebonyi state in Nigeria used qualitative phenomenology to know the experiences of women awaiting fistula repairs at the National Fistula Center (Okoy, Emma-Echieyi, & Tamyi, 2014). With in-depth interviews conducted in the local Izzi dialect, it was transcribed and then translated into English by an expert Izzi writer with great care to ensure that context and nuances of language and choice of words identified by participants were not missing. Although participants could not identify the causes of their conditions, a number of factors were cited as causes of delays in seeking care, and these included powerlessness, poverty, illiteracy, previous negative maternal care services, and absence of basic social services. Since they were viewed as unclean in their communities, patients who successfully had repairs and rehabilitation requested the need for certification of good health to show to their communities. This request shows the ignorance of the community about the disease and the need for community engagement. It also shows the need to educate women about the disease and causes.

Summary and Conclusions

Themes Identified in the Literature

A number of themes emerged in performing this literature search. One theme is that while surgical intervention in obstetric fistulas provides a quick fix, treatment is only effective about half the time or less. Furthermore, the Three Delays are of vital importance because they defer treatment for women in prolonged labor. In addition, even after childbirth, women face the Three Delays to an often unacceptable level as they search for assistance to deal with the fistula. Long-term studies have shown that fistula surgery is not an especially reliable cure for incontinence, and often multiple surgeries are required. Furthermore, no clinical evidence exists at the moment to define the most effective of the many types of surgical intervention that are practiced.

The key concepts in the AAAQ conceptual framework – availability, accessibility, acceptability, and quality of care – provided a useful way of organizing the available literature, though there were often overlaps within individual studies. Most studies address the issue from the basis of quantitative measures: number of patients, length of surgeries, number who appeared clinically successful, and so on. The qualitative studies identified factors such as lack of knowledge about treatment facilities, traditional beliefs, illiteracy, and status of women as contributing factors for delay in seeking care. It also emphasized the education of men and women on safe motherhood and training of traditional birth attendants.

However, in the literature on quality of care there are a few available qualitative studies that showed that the more common quantitative studies, while perhaps easier to

accomplish, fail to reveal the phenomenological experiences of the women with obstetric fistulas. The degree to which these women fail to receive quality care for their condition cannot be ignored.

Gaps in the Research

A number of key gaps were identified in the process of this literature review. For example, there are few clinical studies that define best practices for surgical techniques to repair the fistulas. Management of symptoms before and after surgery is significantly under-researched also. Finding ways to institute needed cultural changes to reduce the early marriage/early pregnancy standards in these nations is another issue. In addition, it is important to discover ways to address each of the four axes of the AAAQ framework. Part of that also means identifying key ways to reduce the Three Delays for women who need emergency obstetric services.

This study is the first to address the phenomenological experiences of women in Sierra Leone who have obstetric fistulas. It is modeled after the anthropological study by Heller (2014), which investigated the experiences of women in Niger, but mediated by the reality of ongoing Ebola considerations that existed in Sierra Leone, where the epidemic created a deep-seated, underlying fear of medical centers (Black, 2015). The recent implementation of motorbike ambulances in rural Sierra Leone may moderate these influences, however (Bhopal et al., 2012). The absence of quality data to inform decision-making continues to serve as barrier to creating the enabling environment for the prevention and care of fistula victims in Sierra Leone. This country is designated as one of the poorest and the worst place to be pregnant, with the highest maternal mortality rate

in the world (UNPF, 2012a). This study addresses these conflicting issues to determine how they impact the overall experiences of women experiencing obstetric fistulas in Sierra Leone.

The following chapter of this dissertation presents in detail the design and methodology of the current study.

Chapter 3: Methodology

Introduction

The purpose of this study, as I described in Chapter 1, was to use a phenomenological approach to understand the experiences and perception of patients with obstetric fistula (OF) and the medical personnel who treat them at AWC in Freetown, Sierra Leone. I designed the study to serve as a platform for advancing national policies and for reducing OF within Sierra Leone. This study was a qualitative, institution-based review of OF patients that provided in-depth information about the problem from semi-structured personal interviews.

In this chapter, I start by describing the research design, the research questions, and the role of the researcher. I then discuss the research tools and instruments, and the pilot study. Next I present details regarding the participants , and conclude with discussions of ethical concerns and trustworthiness.

Research Design and Rationale

The focus of this study was patients with OF and the medical personnel who cared for them at AWC in Freetown, Sierra Leone. To understand the experiences and perceptions of patients with OF and the medical personnel who care for them, I developed four research questions:

1. What are the experiences of OF as perceived by patients?
2. What are the experiences of OFas perceived by medical personnel attending OF patients?
3. What do patients of OF perceive as barriers to medical care?

4. What do medical personnel attending OF patients perceive as barriers to medical care?

The central theoretical framework I used in this study was based on the AAAQ and three delays models. The AAAQ framework calls attention to the availability, accessibility, acceptability, and quality of healthcare at all stages of the care process. It indicates the importance of creating an adequate healthcare infrastructure within a geographical zone while making medical resources physically and economically accessible and culturally and ethnically acceptable (Pacaqnella et al., 2012). This perspective helped me identify themes amongst some common barriers to care, such as delays in individual decisions to seek care as well as patients' inability to get information about a given facility.

Using a phenomenological approach, I addressed the experiences and perceptions of OF patients and the medical staff that treated them through in-depth semi-structured interviews using open-ended questions. A phenomenological approach is used by qualitative researchers when they explore the manner in which specific phenomena appear to humans through their experiences or consciousness (Finlay, 2008). I used this approach to understand the essence of human experiences underlying the phenomenon under study–that is, what experiences were like for the populations under study and what those experiences meant to them. This research helped create the document necessary for successful policies regarding treatment based on varying socio-demographic characteristics within the population. Further, the findings from this study are valuable because they provide information about the way that patients and medical practitioners

perceived the risks and conditions associated with OF. The long-term impact of these results will be their sustained value for treatment of OF, and for patient information and awareness. In creating greater resources for access to information, future patients may be able to gain better access to necessary procedures and create better health outcomes.

The research design involved a 2-month facility-based qualitative data collection process. I engaged treated and untreated girls and women who had lived at least a year with OF. I conducted in Krio and transcribed into English for analysis. This type of assessment was the most comprehensive way to gather evidence regarding participant feedback and interest in the medical processes that could help women with OF. The result of the interview process also indicated the value of future research regarding interview-based interventions in Sierra Leone. This type of design involved the sustained integration of firsthand accounts into the development of procedures necessary for specific and community well-being.

There were several defining elements that made the three delays model and the AAAQ best suited for the study. The three delays model allowed me to explore the barriers to adequate care that caused maternal deaths (see Thaddeus & Maine, 1994). This model was applicable because of the influences in healthcare decision-making that may have limited the services patients could receive. By shedding light on the way that women of reproductive age used information, the three delays model provided a framework that gave me a better sense of roles and tasks of providers to improve the care of OF patients in the future.

Role of the Researcher

Being the principal investigator in this study, it was my sole responsibility to fully plan and execute all aspects of data collection, including recruiting participants, identifying and securing the study site, conducting interviews, and securing and analyzing data. While the nonverbal body language observed in the course of the interviews was recorded, my principal purpose for the interviews ultimately remained the collection of verbal responses from participants. With this, my role required in-depth interviews, note taking, observation of body language, and audio recording of participant responses to interview questions. As a researcher, I also was responsible for data analysis. Although I solicited the services of a second coder/independent investigator to guarantee the accuracy of my interpretations, this individual only analyzed portions of the data identified for comparative purposes. I assumed absolute control of all spheres of data analysis, including the process, final interpretations, and the presentation of final results.

Although I was born in the Eastern Province of Sierra Leone, and I attended high school and university in the Southern Province and Western Area respectively. I had no preexisting relationships with the AWC or its employees and patients receiving fistula repair services at the center in Freetown (Western Area). Because I lacked this connection, I first worked to build rapport with participants to inspire sufficient trust and acceptance through multiple visits to the center (see Creswell, 2007). With improved confidence and understanding of the population, I started the data collection process by asking interview and research questions.

There were several ways that I managed biases in the context of this study. My own biases were set aside as much as possible and my personal agenda managed in a way that did not overshadow the data that was collected from participants. One way of dealing with my own reactions was to be honest with myself and remain self-reflective regarding the processes and the influence of my own reactions. I refrained from being judgmental by tracking my own reactions and thoughts and acknowledging them throughout the research with the goal of preventing my own biases from negatively impacting my data collection and analysis. I used the process of bracketing in the course of data collection and analysis to track my reactions and biases. As Creswell (1998) observed, bracketing is the suspension of one's own judgments and biases by setting them aside from that of the researcher's experience with the bid to limit the influence of researcher on participants. Using a journal to document reactions is one way through which bracketing occurs, and which served as a source of reference for me in the course of data analysis. Journaling helped me meet the goal of distinguishing between what issues or perceptions arose that constituted my own biases and particular positions in the analysis. When researchers suspend what they know in research, they are able to remain conscious of the manners in which they may influence participants. Avoiding biased and judgmental questions was also crucial to this process. I chose only respondents who represented the particular group of interest (OF patients and attending medical personnel). All data was reviewed by an independent analyst, creating a differentiated perspective on the sample and related outcomes.

I therefore evaluated conflicts of interest and power differentials, and the justification for particular incentives or gifts for participants as a mark of appreciation for their time in terms of their potential to interfere with the existing study parameters. I identified few conflicts of interest because I was independent from the institution, so there was no direct connection between me and patients or medical personnel. The outcomes of this study were aimed solely at increasing public knowledge and creating a portrait of the experiences endured by victims of this condition and attending medical personnel. My study therefore posed no significant risk to participants, nor did it lead to degradation of the participants. All threats to ethical practices were eliminated by first adhering to the principles of integrity that require a researcher to be straightforward and honest in all interactions with research participants. Being objective could also be an effective way of eliminating threat to ethical practices. Not allowing bias, conflict of interest, or undue influence of my personal reflections or perceptions to override my professional judgment as a researcher was critical in eliminating a threat to ethical practices. Strict observance of the principles of confidentiality could also be instrumental in eliminating threat to ethical practices. This entailed working to respect the confidentiality of information collected and not disclosing any such information to third parties without the consent of participants, nor using the information to the detriment of the participants or for my personal advantage. Moreover, maintaining high levels of professional behavior by complying with relevant research protocols, such as gaining approval from the research board or institution where the research was due to be

conducted and avoiding any action that might discredit the whole exercise, was an effective mechanism I used to eliminate threats to ethical practices.

Methodology

As a research technique, qualitative phenomenology enabled me to gain in-depth knowledge and understanding of the life experiences and perceptions of 12 patients with OF and eight medical personnel (two physicians and six nurses) who were involved in the treatment and rehabilitation process at AWC in Freetown, Sierra Leone. As Creswell (1998) noted, a smaller sample size for a qualitative study of this nature was appropriate because the fewer the participants, the richer and more in-depth the interview data collected. Since sampling in a qualitative study involves more than just the number of participants included in the study, I gave high consideration to the number of contacts with each participant and the length of each contact until saturation was reached. A smaller sample size was necessary for this study since it was very labor intensive. Analyzing a large sample is often time consuming and impractical. All of the perceptions and experiences that were most important were uncovered with this sample size. I feared that if the sample were too large, data would become repetitive and, eventually, superfluous. Saturation was used as my guiding principle during data collection.

A phenomenological approach was useful for getting participants to explain and interpret their experiences. The AWC currently provides free surgery to women injured in childbirth and has a children's outpatient clinic. The facility has the capacity to deliver 1,200 babies each year in the maternity clinic, treat up to 500 women each year in the fistula clinic, and treat more than 6,000 children each year in the outpatient clinic. The

goal of the AWC is to provide mothers in Sierra Leone with quality surgical care for childbirth-related injuries and help achieve the WHO's MDG 5, which aims to reduce maternal mortality across the developing world.

The population of patients from which I drew participants can be identified as women and girls undergoing treatment at the center. After repair, the fistula patients stayed at the facility in order to await rehabilitation and other reintegration procedures. They were also given skilled training in order to ensure greater levels of productivity and independence when exiting the care environment. Participants were drawn from the fistula patients receiving treatment at the center regardless of age, ethnicity, or region.

I used a justified combination of purposive and snowball sampling strategies for this process. The purposive sampling was essential for identifying initial participants. Since the population for study was readily accessible, purposive sampling was necessary for identifying participants. Verifying that the respondents met the criteria for selection marked my first step in purposive sampling. The snowball sampling was crucial in finding referrals from the initial participants to easily identify additional participants until data saturation was reached. The criteria for participant selection was based on the availability at the facility, expressed willingness to participate in the study, and informed consent in answering interview questions, as well as history of untreated fistula for at least a year for patient-participants. They were also able to speak Krio clearly enough to articulate themselves in terms of their medical history and experiences at the center. The eight medical personnel as specified above were chosen based on their experience with

women with OF, with the aim of engendering diversity in the types of responses that were given.

Instrumentation

One of the instruments designed for this study was the informed consent for patients of fistula receiving treatment at the AWC and their healthcare workers (nurses and physicians), respectively. The socio-demographic information for patients of fistula and their healthcare workers was also collected, as presented in appendix A. In Appendix A, the patient's socio-demographic information included age, region of birth, marital status, level of school education, number of living children, experiences of stillbirth, when fistula developed, employment, religious denomination, household income, and number of years living with fistula; while in the same Appendix B, the socio-demographic information of healthcare workers at the AWC included name or number in place of name, age, gender, job title, department, and the number of years working with OF patients. The interview guide used in this study as shown in Appendix C for patients of OF and their medical personnel (nurses and physicians) consisted of semi-structured interview questions.

Individual in-depth interviews for patients included open-ended questions and probes about their experiences and perceptions of OF. Specific questions and probes relating to experiences and perceptions included the following:

- How did you find out that you had fistula?
- Please describe your experience living with fistula.
- What memories do you have from developing or living with a fistula?

Specific questions relating to barriers to care included the following:

- Tell me about things that prevent you from seeking care.
- How has this changed since you began leaking?

Moreover, there were spontaneous questions aimed at understanding patients' level of social support, such as "Tell me about people who are most important in your life," and "How have your relationships changed since you started leaking?" Patients were also asked about coping through questions such as "Tell me how you deal with your problem." The in-depth interviews were conducted in the Krio language by me, since I can fluently read, write, and speak it as a Sierra Leonean myself. All these instruments were also translated into English. The interviews lasted approximately 40–80 minutes each.

The first two questions described above investigated what patients of obstetric fistula perceived as barriers to medical care. This was a greatly subjective question that required the input of the patient as it was needed to figure out why more people were not receiving care. Interviews with patients were the greatest source of information to illustrate this point.

The use of semi-structured interviews with open-ended questions as a data collection instrument was essential, particularly in the case where the researcher was familiar with the issues under investigation but faced difficulty in predicting individual responses to a particular question and therefore effectively structuring the answer. A semi-structured interview guide was also advantageous as it favored an informal setting where I and participants could freely interact. Such a conducive atmosphere encouraged

participants to respond to interview questions in the language that was most convenient to them. A semi-structured interview further helped the researcher to delve deeply into a particular question that suited the comfort of the researcher and the respondent alike, as it paved the way for the researcher to obtain adequate and rich data on the basis of the interview guide. In such a situation, the researcher maintained effective control over the direction of the interview while at the same time the respondent maintained control over the information provided.

Since the study participants were mainly patients receiving treatment at AWC and their attending medical personnel, the researcher found it relatively easy to repeatedly visit the center in the daytime, which made it comfortable for respondents to freely respond. Frequent visits and in-depth activity of participants were crucial for relationship building between researcher and respondents and for the free flow of information.

Tape recorders were also used as an important data collection instrument with participants' permission in order to adequately capture data. One set of interviews was completed per weekday. Information gathered in Krio from each individual was compared and contrasted individually after being transcribed into English.

Another important research question addressed in this study was the perception of medical personnel (two physicians and six nurses) attending obstetric fistula patients towards barriers that patients may have had towards medical care. This was an important objective that could be realized through the investigator-created interview question. The results from interviews with the medical center personnel ultimately illustrated the barriers to change that were experienced in the daily care of OF patients.

Overall, this study aimed to collect and analyze the best information regarding practices that could be engaged in on behalf of patients in the future to create progress in decision-making by medical professionals and patients about care of OF. Therefore the attention to patient decisions and medical staff interpretations provided a variegated portrait of the way that systems can change. It also laid the foundation for additional research about patients with this condition in Sierra Leone, promoting future studies to drive change within the patient education process.

For Researcher-Developed Instruments

I have created interview questions for this study for patients of OF and their medical personnel (see Appendix C). The primary objective of the study was to acquire information from fistula patients and their healthcare workers within the AWC in Sierra Leone about their experiences and perceptions of living with the disease and caring for the patients, respectively. Each of the interview prompts were designed to gather useful qualitative information that the field heretofore has not had access to. Content validity was established based on the consistent documentation of information and trends regarding participant responses. It was possible for a comprehensive image to be created of the trends in patient decision-making based on these questions that were relatively open ended and required specific input from the patient. With implementation within the medical center these interview questions were highly efficacious for collecting patient and medical staff perspectives alike.

Procedures for Pilot Studies

To ensure that the interview questions were relevant, valid, and culturally acceptable, I conducted a pilot study by purposefully selecting three key participants. Two were recruited from a renowned maternity clinic within the Twin Cities in Minnesota. Eligible participants needed to be a woman between 18 and 65 years and a West African born with extensive experience directly treating patients of OF in that region in the past for at least a year. A semi-structured interviewing technique with in-depth and open-ended questions designed for medical personnel in the actual study were used to explore their experiences and perceptions of OF and barriers to care. In the same vein, one woman who lived in the Twin Cities aged between 18 and 65 who was a West African born with no formal education and had once been familiar with OF patients while in West Africa was recruited to participate in the pilot study by answering the same set of interview questions designed for OF patients in the actual study. The pool of contacts for participants was expanded with the use of snowballing using participant referrals. Eligible, consenting individuals were interviewed in person at a location selected by the participants. All questions were administered in English. Each interview required approximately 1 hour in total to complete. At the end of each interview, participants received a lip balm and snacks as a thank you for their time and participation.

The pilot study helped identify potential practical problems in following the research procedure thereby devising precautionary safety nets. As such, the pilot instrument was designed to invite comments about the perceived relevance of each question to the stated intent of the research. Participants were also provided the

opportunity to suggest additional questions that I did not include. The time to complete the interview questions was recorded, which was helpful in determining whether it was reasonable. The findings of the pilot study were reported in detail. Any actual improvement noted to the study was also explained. However, data from the pilot were not included with data from the main study because they were not from the AWC in Freetown, Sierra Leone. Also, participants in the pilot study did not participate in the full study since they were not from the AWC in Freetown, Sierra Leone. This pre-testing increased the assurance that the research instrument could be used properly and there was consistency in information obtained.

Procedures for Recruitment, Participation and Data Collection

Because it is one of the most hidden maternal health problems, finding victims of OF could have been very difficult. This was further exacerbated by the difficulty of identifying health facilities that conduct fistula repairs, particularly in poor-resourced settings like Sierra Leone. Fortunately, in Sierra Leone, Mercyship, which is an International Non-Governmental Organization, established the Aberdeen West African Fistula Center, which has been renamed the Aberdeen Women's Center, for the repair of fistula.

The Center currently provides free surgery to women injured in childbirth and has a children's outpatient clinic. The facility has the capacity to deliver 1,200 babies each year in the maternity clinic, treat up to 500 women each year in the fistula clinic, and treat more than 6,000 children each year in the outpatient clinic. The goal of the AWC is to provide mothers in Sierra Leone with quality surgical care for childbirth injuries and

help achieve Millennium Development Goal 5, which aimed to reduce maternal mortality across the developing world. The center was staffed by a combination of medical and administrative personnel that included visiting physicians/medical officers, community health officers (nurses and midwives), and community health educators.

The study was conducted in the Department of Obstetrics and Gynecology within the AWC, where free-of-charge fistula repairs were conducted. It is worth noting that patients admitted at this center generally underwent reparative surgery within two to three weeks and stayed in the OF ward for as long as one month after surgical repair. OF patients admitted at the Center at the time of the study with at least a one-year history with OF were qualified to participate. Those OF patients admitted at the Center who were seriously sick, deaf, or mentally disoriented, and determined not capable to provide informed consent or information relevant to the study, were excluded from participation.

Approximately a month before my arrival in Sierra Leone for data collection, flyers that indicated the research process and eligibility criteria for participation as well as contact information were available to the clinic (see Appendix D and E). AWC's management and staff were relied on for the distribution of flyers to potential participants who requested information. The consent form was also available to potential participants at the Center, and was marked to indicate the ones that applied to fistula patients or their healthcare providers. Information about inclusion as specified in the flyers helped participants to determine their eligibility and facilitated their recruitment. Although these documents were helpful in the recruitment process, extra screening questions were available to confirm participants' eligibility (see Appendix A and B). The screening

questions were frequently used by me to ensure that the right and eligible participants were interviewed.

It was also worth noting that AWC was chosen for this study because it was located in the most populous city in Sierra Leone with a high degree of ethnic and cultural diversity. With the difficulty of identifying victims of OF, a snowball sampling technique was used. Through the use of this technique, patients with OF in the AWC who were willing to participate in the study were contacted with the help of the Center's management and staff. This snowball technique created room for willing participants to suggest other patients they knew who could be also take part in the study. It was also important to note that women suffering from this common problem were encouraged to form a strong bond as part of their coping strategy. In the case where the women being studied were well connected but hard to reach directly, or when social networking was crucial to the study, the snowball sampling method was important. The interviews were conducted in the center's interview room, which had a door that could be closed to guarantee participants' privacy.

The inclusion or exclusion of participants was not based on social background, economic circumstance, demographics, or age. Therefore, the data was collected from all eligible participants in the study. Being a patient of OF receiving treatment at the AWC at the time of data collection or being medical personnel at the center qualified individuals for participation.

The 40 to 80 minutes of questions for patients of OF focused on their perceptions about barriers to medical care and the experiences of living with such a health condition.

While the interview questions for medical personnel focused on their perceptions and experiences working with fistula patients, barriers encountered, and strategies adopted to cope with the challenges.

With the IRB approval, permission to conduct interviews was obtained from the Aberdeen Women Center in Freetown, Sierra Leone. Written and verbal informed consent was obtained from each participant. Participants could have exited the study at any time they deemed necessary. They were informed of the confidentiality of their responses as well as the research interests behind using these methods of data sampling and analysis. Since this was a one-time study that will gather the evidence necessary within a predetermined and allocated setting, there were no follow-up interviews for individuals or the medical staff. Data was recorded in Krio using audiotapes and note taking. This recording process created a set of firsthand accounts in the language of the individual participants. The follow-up plan for these procedures in the event that too few participants were found would be to extend the length of the study in the care setting until an appropriate number of responses were acquired.

Data Analysis Plan

The primary type of data that was collected was comprised of the qualitative responses of interviewees. In creating a comprehensive assessment of these results, it would become possible to gather certain evidence regarding each research question. Data analysis started after all of the in-depth interviews were over; it used Hycner's phenomenological analysis of the interview data, which was interpreted and organized through the identification of emerging themes that added to rich descriptions of the

phenomenon, based on the participants experiences and perceptions (Hycner, 1985). This started with transcribing the audiotapes, with strict observance of the rules of transcription. The second crucial step was coding or identification of participants' words or phrases with great attention to responses that were essential to the study. The coding procedures required for this study involved translation of interview materials from Krio to English. This was done by me and a second coder who was a native Krio speaker who had been educated and qualified in English to provide accurate translated results. The data was transcribed verbatim into English. Categorization of identified information then followed. Statements that were crucial to the study were clustered into themes, which formed the basis of the study (Hycner, 1985). Results thus appeared as themes based on the experiences and perceptions of the participants and medical personnel, placing great emphasis on the AAAQ model and the Three Delays model.

Based on the requirements of Hycner (1985) for reliability, the services of an independent judge were secured to check for the reliability of units of relevant meaning and provide a basis for comparison and confirmation. I consulted with my dissertation committee should discrepancies emerge. The independent judge was trained using Hycner's requirements.

Trustworthiness

A qualitative study's credibility is measured by using validity and reliability. LoBiondo-Wood and Habber (1994) described validity as an evaluation of the correctness of the method chosen to accurately reflect the concept that it is designed to measure. For this to be ensured, I gave much attention to expert judgment, particularly

that of my committee members. The instruments used in this study were validated through constant discussions with my committee members, statisticians, and colleagues. Appropriate adjustments were made to improve the quality and relevance of data collected.

As also noted by Mugenda and Mugenda (1999), reliability is considered a measure of the degree to which a research instrument yields consistent results or data after repeat trials. For reliability to be maintained, the interview schedule was piloted prior to its use in the actual study. I carried out pre-tests of the instrument using three key participants two of whom were from the maternity ward in a renowned clinic within the Twin Cities in Minnesota and one from within the community in Brooklyn Park with no formal education who articulate their experiences as they related to the phenomena being investigated, obstetric fistula. Information obtained from the study was used to (a) evaluate reactions of research participants to the study procedure; (b) determine the day of the week and time of the day when eligible informants will be available, and the appropriateness of meeting location; the acceptability of interview questions; and the willingness of participants to take part in the study. For data to be adequately collected, recorded, and filed, the availability of required tools such as interview questions and an audio recorder were crucial. All these measures determined whether or not the data collected were of acceptable standards in terms of relevance, validity, and reliability.

Through triangulation, saturation, and reflexivity, internal validity could be assured in these trials. For example, a prolonged engagement with participants in their environment allowed for a variegated collection of information. Further triangulation was

possible in this study because of the same question being administered to multiple subjects and audiences.

Strategies aimed at transferability or external validity could be identified as well. In making generalizations about the study results, some caution needed to be taken because of the small size of participants even though it did not serve as a total barrier. This was because the problem related to sampling and generalization had little relevance to the goals of the study and the reality of the situation. It has been argued (Myers, 2000) that in most situations a small sample size may be more relevant in assessing a situation in-depth from various perspectives, whereas a large sample size could be inconsequential. Since the goal of this study focused on the contemporary phenomenon of OF, where in-depth descriptions were an essential component of the process, a small sample size or qualitative study could offer a more personal understanding of the phenomenon, and the results could potentially contribute valuable knowledge to the community. Using generalizability as a potential factor, this qualitative study may however be rebuked by critics due to the fact that it may be difficult to replicate since future researchers may not have access to the same participants, and if other participants are used, the same results may not be produced (Myers, 2000). It was also my fear that respondents may openly communicate with me and maintain distance with another researcher. This did not however preclude the redeeming features which made qualitative study of this nature highly valuable in the education community. The research objectives can be understood in terms of the specific population but may require a greater assessment of more interviewees for larger qualitative generalizations. Therefore, transferability was limited

in this study. Transferability means that a study's findings and conclusions are applicable to other situations or populations (Bowen, 2005).

Further, certain strategies can help demonstrate reliability in small-sample qualitative studies. In this study, an audit of trials and triangulation created dependability. The ultimate reliability of this study was demonstrated on the validity of its conclusions. As observed by Golafhani (2003), validity and reliability are two factors which any qualitative researcher should be concern about when designing a study, analyzing results, and judging the quality of the study. Golafhani (2003) further stressed that an examination of trustworthiness was crucial to ensuring reliability and validity in qualitative studies. Since there can be no validity without reliability, Lincoln and Guba (1985) maintained that the demonstration of validity was sufficient to establish reliability. In this study, triangulation was typically a strategy for improving validity and reliability.

In addition, in this study, confirmability was demonstrated in terms of reflexivity and intra-/inter-coder reliability. This research brought a unique perspective to the overall study of patient medical access and perceptions. By checking the data continuously and allowing another research associate to be involved with the analysis, the confirmability of results was enhanced. Conducting a data audit at the end of the study also allowed for the judgments and procedures within this trial to have lasting and confirmable results.

Finally, being a key part of the logic of validity testing, discrepant data was potentially avoided in this study by establishing a plain and simple standard operating procedure that was easy to follow by participants. Every step of the process was double-checked to ensure that it was to the participant's level of understanding. At the

completion of each interview, I offered participants an opportunity to validate accuracy of their words and carefully examine unusual contradictory results for explanations. Furthermore, I double-checked each participant's information, and where discrepant data was identified, I reported it and allowed readers to draw their own conclusions.

Ethical Procedures

To ensure a high standard of professional research ethics in this study, I adhered to all ethical research practices. First, permission to conduct research in a health center in Sierra Leone was requested and obtained from the Ministry of Health and Sanitation (see Appendix F). Familiarizing myself with the National Code of Health Research Ethics established by the National Health Ethics Committee was crucial in order to ensure that the study plans met the requirements of ethical protocols with reference to social value, methodological validity, recruitment of participants, informed consent, and respect to the principles of confidentiality in the course of the study. Secondly, Walden University's Institutional Review Board approval, with clearly stated approval number and expiration date (09-16-16-0276483), was secured before data collection.

Prior to my arrival in Sierra Leone for participant recruitment and data collection, I facilitated effective networking with the AWC's management and staff with the aim of gaining their permission and propagating the news about the study through flyers. The process of recruitment also included the submission of copies of consent forms to the clinic's management and staff so as to make them available to potential participants who exhibit interest in the study. Even though these materials were made available to would-be participants through the Center's management and staff, the actual recruitment was

done by me for the purpose of adhering to the principles of confidentiality. Any doubt expressed by participants relating to the study was directed to me for clarification either through email, phone, or in-person while I was in Sierra Leone.

Because of my awareness of the vulnerability of the target population, all efforts were exerted to protect them from exploitation and the undermining of their human dignity by presenting the appropriate consent form with a full explanation of the benefits and implications for participating in such a study in the language most comfortable for them. Sufficient time was given to them to increase their understanding of the voluntary nature of their participation, including no element of duress and the assurance of withdrawal with no repercussions should they feel otherwise. The information I included on the consent forms using Walden University templates was comprised of an introduction of who I was as the researcher, background about the study purpose, inclusion criteria that emphasized participants' expectations, the voluntary nature of the study, and benefits and risks of participation. Participants' privacy and the contact information of the university and myself that could be crucial in times of questions was also included.

Because OF is one of the most hidden maternal health problems and is rarely discussed by victims, and because of the emotional stress and shame many victims had been previously subjected to in their various communities, I allowed them to stop participation whenever requested until they were emotionally prepared to continue. Nurses at the AWC were also encouraged to provide counseling services to participants who felt stressed or upset while recalling the agonies of their past experiences.

As a means of ensuring the ethical consideration of the confidentiality of participants, participants' chosen pseudonyms were used. The pseudonyms were chosen by participants themselves as a confidence-building strategy. Concealing the personal information of participants at the time of data collection prevented them from being identified by the second coder/independent investigator who was presented with collected data for analysis.

Since the study aimed to provide evidence as a platform towards advancing national policies for the reduction of obstetric fistula within Sierra Leone, the study results were shared with the AWC via email or presentations. As a means of increasing awareness about the severity of OF in Sierra Leone, I shared results of the study with health policy-makers, the National School of Nursing, the College of Medicine, and organizations that promote maternal health, via hand delivery, email, or local mail. Professional and academic arenas were also targeted for information-sharing about the research results through conferences and publications in scholarly journals.

Several other ethical issues within this project were taken into consideration. No offer of monetary incentives was made to participants. Since participants were met in the facility where they were admitted and receiving services, no traveling expenses were covered. However, because participation in the study was time-consuming, snacks were provided during interviews, as well as one deodorant as a thank-you gift for their time. Since nurse counselors were needed to counsel participants who exhibited signs of emotional stress as a result of their reflection and recollection of their experiences living with fistula, they were presented with a small thank-you gift for provision of such

services during the interviews. These incentives were not problematic since the research participants did not participate in the interview because of the incentives.

Further, the information was protected and stored in a way that was safe and mitigated the risk of corruption. Initial reports in Krio as well as the English translations were safely stored. These were valuable towards the overall integration of results in the data and analysis process. The involvement of a second coder with samples of identified data for analysis did not guarantee access to the data storage location. Electronically stored data was protected with a password on my personal computer. The digital recorder and hard copy documents were also kept under lock and key in my home cabinet, to which I was the only person with access. These safety procedures remained unchanged regardless of any change of location. Having two electronic flash drives and a locked box for hard copies during travel from Sierra Leone to the United States ensured data security and protection. The original data will be destroyed after five years in line with Walden University's requirement.

Summary

In this chapter I described how the qualitative phenomenological approach was used to collect data with the aim of developing an in-depth understanding of the experiences and perceptions of patients with OF and their attending medical personnel in AWC. I shed light on the interview protocol designed for data collection from 12 patients with OF and eight medical personnel (two physicians and six nurses) at the AWC through individual interviews in a semi-structured format. Data was collected in the Krio language and transcribed into English for analysis. Data collected was interpreted and

organized by themes using Hycner's (1985) method of content analysis for phenomenological data. To ensure the reliability of my data analysis, inter-coder reliability testing was conducted and took into account a high percentage agreement index indicative of reliable analysis. Additionally, data analysis procedures and conclusions regarding the ethics and trustworthiness of the study were provided.

Chapter 4: Results

Introduction

My objective in this study was to explore the experiences of patients with OF and their medical personnel in Sierra Leone. To meet this objective, I conducted interviews with patients, nursing personnel, and fistula surgical doctors at the AWC in Sierra Leone in the span of 2 months. This chapter includes a description of the study findings. The following overarching research questions informed this study:

1. What are the experiences of OF as perceived by patients?
2. What are the experiences of OF as perceived by medical personnel attending OF patients?
3. What do patients of OF perceive as barriers to medical care?
4. What do medical personnel attending obstetric fistula patients perceive as barriers to medical care?

In this chapter, I offer an overview of the pilot study, discuss study results, and provide detailed analysis using information collected from all the standard open-ended interview questions for both the fistula patients and their healthcare workers (see Appendix C). The general ideas expressed by the participants were captured in the data, which I organized into categories and emerging themes. Details of the research setting and evidence of trustworthiness are also presented, as well as a summary of the results.

Pilot Study

Prior to the main data collection, I obtained approval from Walden University's the Institutional Review Board, the study tools pre-tested with three West African women

in the Twin Cities in the space of three weeks to ensure that the interview questions were relevant, valid, and culturally acceptable. Two were West African-born nurses (aged 37 and 42) who had previously worked with fistula patients in Liberia and who were currently employed at Hennepin Medical Center in Minneapolis, Minnesota. The third was a 62-year old Sierra Leonean woman with no formal education who had experience in caring for a fistula patient 15 years ago in rural Sierra Leone. The nurses answered the interview questions designed for healthcare workers; their interviews were conducted in their homes on their days off. The 62-year-old woman responded to questions designed for fistula patients at her apartment in Brooklyn Park, Minnesota. The face-to-face interviews helped me assess validity by comparing the responses to the interview questions with the participants' real opinions as they recalled their past experience relating to disease while caring for patients. Some of the questions were asked in more than one way to assess internal consistency. I determined acceptability by asking participants how they found answering the interview questions during the validity testing. This process was essential in helping to identify the main issues and also form the basis for the questions to be used in the final study, for both fistula patients and their health care workers. Even though I made no changes to the data collection tools as a result of the pilot study, it nonetheless prepared me to be calm, not emotional, attentive to details, and better adjust my time management style.

Study Setting

I conducted this study behind closed doors in a room at the Department of Obstetrics and Gynecology of AWC located at the west end of Freetown, Sierra Leone.

The center provides free-of-charge fistula repairs for women injured in childbirth. It is a 180-bed capacity clinic that hosts both a maternity ward and a fistula ward. The center has a 95-bed OF special ward established in 2005, and generally receives patients from all over the country because it is the only recognized fistula repair center in Sierra Leone. Patients admitted at this center generally undergo reparative surgery within 2 to 3 weeks of their arrival from the rural areas, and stay in the OF ward for as long as one month after surgical repair. The center is staffed by a combination of medical and administrative personnel that includes visiting physicians/medical officers, community health officers (nurses and midwives), and community health educators. Since its inception in 2005, the center has reported an increasing number of fistula cases (up to 500 each year). At the time of the study, the center had conducted surgical repair for approximately 28 patients. 24 more patients were brought in from the provinces by the center's screening team on the last day of the study. These women who were admitted for repair of OF and who had lived with the condition for a year or more were approached and invited to participate in the study.

Demographics

Patients' Socio-Demographic Characteristics

In totality, 12 patent participants between 18 and 23 years old participated in the face-to-face semi-structured interviews. The median age of patient participants in this study was 19.73 years of age, with one patient participant failing to state her age due to lack of knowledge of the year of her birth. They had lived with a fistula for a period ranging from 1 year and 1 month to 3 years and more. All patients reported being married

before developing fistula. With the exception of 2 who were still married and 2 who were widowed, the rest reported being divorced/separated. They all had a fistula following a stillbirth. The face-to-face interviews took place in an isolated location within the AWC, which was extremely critical for the patients to freely and coherently discuss their experiences living with fistula and barriers to care. The socio-demographic data of the patients who participated in interviews in this study are shown in Table 1.

Table 1

Patient Socio-Demographics

Patient	Age	Town & Region of Residence	Marital Status	Primary Education	# Living Children	When Fistula Developed	Employment	Religion	Household Income	Years w/Fistula	Current Treatment
1	20	MaranpaMashimera- Port Loko District	Divorced	N/A	N/A	Yes	N/A	Muslim	Farming	3+ years	Yes
2	18	Kono, East Province	Divorced	Yes	N/A	Yes	Family Farming	Christian	Farming	1 year, 1 month	Yes
3	21	Babala, Port Loko District	Married	N/A	1	Yes	Family Farming	Muslim	Farming	1 year, 8 months	Yes
4	20	Mashiaka, Tonkolili District	Married	N/A	2	Yes	N/A	Muslim	Farming	1 year, 7 months	Yes
5	23	CotaBeshele, Bombali District	Divorced	N/A	3	Yes	N/A	Muslim	Farming	1 year, 6 months	Yes
6	18	Kaya, Kambia District	Divorced	Yes but stopped at Junior Secondary School	N/A	Yes	N/A	Muslim	Farming	1 year, 4 months	Yes
7	19	Port Loko, Port Loko District	Divorced	Yes, stopped at Class V	1	Yes	N/A	Muslim	Farming	1 year, 1 month	Yes
8	19	Kono, East Province	Divorced	Stopped at Junior Secondary School	N/A	Yes	N/A	Muslim	Farming	1 year, 6 months	Yes
9	18	Mashiaka, Tonkolili District	Widow	N/A	1	Yes	N/A	Muslim	Farming	1 year, 6 months	Yes
10	21	Bindi, Koinadugu District	Divorced	N/A	N/A	Yes	N/A	Muslim	Farming	2+ years	Yes
11	?	District	Divorced	N/A	N/A	Yes	N/A	Muslim	Farming	2+ years	Yes
12	20	Kono, Kono District	Widow	N/A	2	Yes	N/A	Muslim	Farming	1 year, 2 months	Yes

Medical Worker/Nurse Socio-demographics

There were six medical worker nurse participants in this study. The median age of nurse participants in the study was 38.17 years of age, and the median years of experience for nurses in the study working specifically with fistula patients was 6.9 years. Table 2 lists the demographic data for nurse participants in the study.

Table 2

Nurse Socio-demographic Data

Nurse	Age	Gender	Department	Years working with fistula patients
1	36	F	Vesicovaginal Fistula (VVF)	5 Years
2	39	F	VVF	10 Years
3	30	F	VVF	6 Years
4	54	F	Operation	11 Years
5	34	F	VVF	5 Years
6	36	F	VVF	4 Years

Fistula Surgeon Participant Demographics

There were two fistula surgeon participants in this study, and both were female surgeons, 38 years of age, with a median practice experience working as fistula surgeons of 12 months. Table 3 shows the demographic data for the fistula surgeon participants in this study.

Table 3

Fistula Surgeon Participant Demographic Information

Surgeon	Age	Gender	Length of time worked with fistula patients
1	38	F	1 Year 6 Months
2	38	F	6 Years

Data Collection

The interviews were conducted at the Department of Obstetrics and Gynecology within the AWC in the interview room behind closed door to guarantee participants' privacy. Approximately, a month before my arrival in Sierra Leone for data collection, flyers that indicated the research process and eligibility criteria for participation as well as contact information were available to the clinic (see Appendix D and E). AWC's management and staff were helpful in the distribution of flyers to potential participants who requested information. The consent forms were also available to potential participants at the center, and were marked to indicate those for fistula patients, and those for their healthcare providers. Information about inclusion as specified in the flyers helped participants to determine their eligibility and facilitated their recruitment. Although these documents were helpful in the recruitment process, extra screening

questions were available to confirm participants' eligibility (see Appendix A and B). I obtained written and verbal informed consent from each participant.

I drew a purposeful sample of 12 fistula patients (P), six nurses (N), and two fistula surgeons (FS) at the AWC. Inclusion criteria for patients were: OF patients admitted at the center during the study who had lived with the health condition for a year or more, were 18 years of age, and were willing to participate by giving their consent. Exclusion criteria were OF patients admitted at the center who were seriously sick, deaf, or mentally disoriented and not capable of providing informed consent or information relevant to the study. Criteria for healthcare workers inclusion were: being employed at AWC at the time of data collection and being a nurse or fistula surgeon treating OF patients for at least 1 year.

In addition to note taking, I used audio recorders, with participants' permission, as important data collection instruments in order to adequately capture data. I completed one set of interviews per weekday. Data was recorded in Krio using audiotapes and note taking in English. This recording process created a set of firsthand accounts in the language of the individual participants. I compared and contrasted information gathered in Krio from each individual after transcribing it into English.

There was however a variation to data collection that involved the audio recordings of the interviews, as they were not effective or possible, as I identified in Chapter 3. This variation occurred as a result of technical constraints with the software recording application. The interview process was never hindered by this variation simply because the interviews and transcription were done simultaneously and returned to

various participants for member checking. Even though probing questions were asked as specified in the interview questionnaire, I made all efforts to avoid leading the participant in their responses, and to ensure that explanations were solicited as deemed necessary. Each interview lasted for not less than 45 minutes and not over 80 minutes.

I was careful to employ probative questions identified on the interview questionnaire (see Appendix C) in order to avoid leading the participant in question responses.

Data Analysis

I imported the data collected from the interviews questions into Nvivo 10 software, which revealed characteristics and variables. This software allows contents to be organized according to themes using a process called coding. I created a hierarchy of 38 themes through the coding process, which included 20 main themes and 12 subthemes. Some of the themes include: (a) many women experience financial barriers to getting medical care; (b) preference for local traditional healers serves as barrier to medical care; lack of awareness about fistula and treatment options prevented patients from seeking care; (c) modern healthcare workers display ignorance and arrogance; (d) fear of Ebola prevented some women with fistula from seeking medical care; (e) many women with fistula feel abandoned, deserted, and shunned; (f) women are becoming hardened, bitter, and hopeless; (g) fistulas can lead women to depression and emotional distress; (g) financial survival became more difficult during and after treatment; (h) despite challenges, many women experienced the work of good Samaritans; (i) for some, there was a fear of toxic gossip; and (j) some women with fistula were miserably affected by paralysis and foot dragging (see Tables 4 and 5 for a complete list of themes). As part of the analytic

process, I further refined the themes, and organized and analyzed them using Hycner's (1985) phenomenological analysis of interview data. Through the use of matrices and queries created with Nvivo 10 software tools, I explored patterns and comparisons among themes. In order to enhance easy understanding and communication, selected results were converted into charts and tables, which I have included in this report. It is worth noting that the Nvivo database containing the data sources, coded data, coding scheme, analysis, and graphics is an interactive tool that can continue to be manipulated to provide additional configuration of data for ongoing exploration and analysis.

Evidence of Trustworthiness

My role as researcher in this study was to explore the experience of obstetric fistula from the perspective of the patient, while the secondary role was to explore the perspectives of medical staff treating fistula patients. For trustworthiness to be ensured, I gave much attention to expert judgment, particularly that of my committee members. The instruments used in this study were validated through constant discussions with my committee members and colleagues. Appropriate adjustments were made to improve the quality and relevance of data collected.

As a way of establishing credibility, IRB approval and permission to conduct interviews were obtained from Walden University and the Aberdeen Women Center in Freetown, Sierra Leone respectively (See Appendix G, H&K). Screening questionnaire was utilized to confirm participants' eligibility (see Appendix C). The screening questions were frequently used by me to ensure that the right and eligible participants

were interviewed. Interview questionnaire was also utilized to get the perspectives of the patients and their healthcare workers.

In order to maintain reliability, the interview schedule was piloted prior to its use in the actual study. I carried out pre-tests of the instrument using three key participants two of whom were from the maternity ward in a renowned clinic within the Twin Cities in Minnesota and one from within the community in Brooklyn Park with no formal education who articulated their experiences as they related to the phenomena being investigated, obstetric fistula. Information obtained from the study was used to (a) evaluate reactions of research participants to the study procedure; (b) determine the day of the week and time of the day when eligible informants will be available, and the appropriateness of meeting location; the acceptability of interview questions; and the willingness of participants to take part in the study. For data to be adequately collected, recorded, and filed, the availability of required tools such as interview questions and an audio recorder were crucial. All these measures determined whether or not the data collected were of acceptable standards in terms of relevance, validity, and reliability.

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because of the small size of participants even though it did not serve as a total barrier. This was because the problem related to sampling and generalization had little relevance to the goals of the study and the reality of the situation. It has been argued (Myers, 2000) that in most situations a small sample size may be more relevant in assessing a situation in-depth from various perspectives, whereas a large sample size could be inconsequential. Since the goal of this study focused on the contemporary phenomenon of OF, where in-depth descriptions were an essential component of the process, a small sample size or qualitative study could offer a more personal understanding of the phenomenon, and the results could potentially contribute valuable knowledge to the community. Using generalizability as a potential factor, this qualitative study may however be rebuked by critics due to the fact that it may be difficult to replicate since future researchers may not have access to the same participants, and if other participants are used, the same results may not be produced (Myers, 2000). It was also my fear that respondents might openly communicate with me and maintain distance with another researcher. This did not however preclude the redeeming features which made qualitative study of this nature highly valuable in the education community. The research objectives can be understood in terms of the specific population but may require a greater assessment of more interviewees for larger qualitative generalizations. Therefore, transferability was limited in this study. Transferability means that a study's findings and conclusions are applicable to other situations or populations (Bowen, 2005).

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In addition, in this study, confirmability was demonstrated in terms of reflexivity and intra-/inter-coder reliability. This research brought a unique perspective to the overall study of patient medical access and consequences living with OF. By checking the data continuously and allowing another research associate to be involved with the analysis, the confirmability of results was enhanced. Conducting a data audit at the end of the study also allowed for the judgments and procedures within this trial to have lasting and confirmable results.

Finally, being a key part of the logic of validity testing, discrepant data was potentially avoided in this study by establishing a plain and simple standard operating procedure that was easy to follow by participants. Every step of the process was double-checked to ensure that it was to the participant's level of understanding. At the completion of each interview, I offered participants an opportunity to validate accuracy of their words and carefully examine unusual contradictory results for explanations.

Furthermore, I double-checked each participant's information, and where discrepant data was identified, I reported it and allowed readers to draw their own conclusions.

Results

The results of the study are presented below in four sections: the socio-demographic characteristics of patients, nurses, and surgeons; fistula patients' perceived experiences living with fistula and barriers to care; nurses' perceived experiences of patients living with fistula and barriers to care; and surgeons' perceived experiences of patients living with fistula and barriers to care. Each of the research participants' perceived experiences and barriers to care are presented according to the various themes that emerged. The themes throughout this chapter are supported by direct quotes from the participants who the researcher has identified as similar in nature. Although similar, each participant's perspective is unique and important in its own right. However, themes allow us to organize the data and make similarities more explicit. These patterns of similarities will help us find meaning in the results.

Patient Interviews

RQ1: What are the experiences of obstetric fistula as perceived by patients?

In the analysis of the experiences of OF as perceived by patients, 7 themes constantly emerged. The 7 themes were: Abandonment, desertion, shunning; becoming hardened, bitter, and hopeless; depression and emotional distress; difficulty of financial survival during and after treatment; good Samaritans; fear of gossip; and paralysis and foot dragging. From the description of their experiences living with OF, patient participant responses indicated a great deal of interrelatedness and occasional overlapping

of all seven themes. The patients' experiences were generally alarming due to the untold suffering characterized by pain, shame, societal stigmatization, and coping strategies. All these elements as expressed in their responses cut across all seven themes and also presented separately (Figure 1).

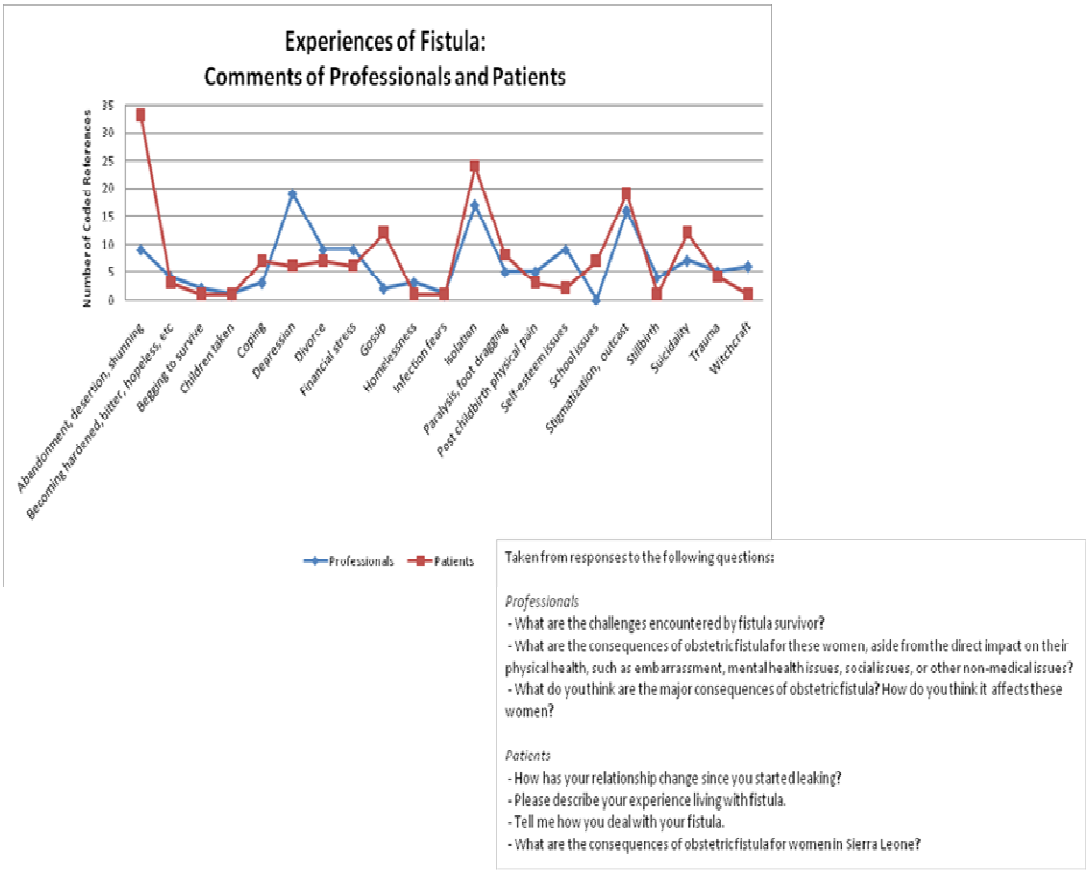

Figure 1. Experiences of fistula.

Theme 1: Many Women With Fistula Feel Abandoned, Deserted, and Shunned

Most patients with obstetric fistula felt that they had been isolated from and abandoned by their families and communities. They felt a lack of association with any other human beings, as they are shunned by those whom they have known their whole lives. They were dejected because they had been rejected. Their lives before this had been

very social, including participation in religious practices, which were performed as a group in the community, but from which they were now prevented from participating. Some in the community were simply indifferent to their suffering, but others were actively hostile, such as accusing a woman of practicing witchcraft and casting her out of the community because of her urine leakage. They were more worried about letting the bunch of old clothes between their legs that held their urine not to fall out in public and face further embarrassment.

Participants' responses included the following:

With fistula, I was deserted by my husband and my family…he quickly tried to find his way out of the mess. He could not withstand my urine smell and he drove me…No love…Early in the morning I started walking out of the town to nowhere with no money. My socked cloths bundled up on my head became so heavy for me to carry and I finally decided to leave it in the bush and continue my journey to nowhere…I had the greatest shock of my life when I arrived in Waterloo. While walking to my uncle's house, I came across one family who strictly warned me not to venture to my uncle's as the news of me being a witch from the village has met them. I ignored the advice and proceeded to the house. The first glance of my uncle on me was the most terrible moment for me. He wasted no time in declare that I am a witch and that I should not enter his house. He ordered the children to sing behind me and also stone and beat me…I ran for safety into an unfinished house where I hid myself from the children and I was not seen. After I

was confident that no one of the children were out, I slowly came out of the hiding and continue my endless journey in the street. (P01)

> When I started leaking, I was deserted by my husband…I lost all family and husband support when my fistula case got worst. I was totally abandoned…Unfortunately my mother's boy friend could not allow me to live with them due to my urine odor. I remained an outcast till the end of the Ebola crisis when my aunt brought me to Aberdeen Women Center. (P03)
>
> When I developed fistula all those that are crucial in my life deserted me…I was beaten in the society bush to confess that I am a witch…The beating did not cause me to confess and they abandoned me in the society bush. While in the bush knowing full well that there is nobody in the village to protect me and provide care for me, I decided to walk to my mother who was living almost 17 miles away in another village…To my greatest surprise, my mother refused to allow me to stay with her. Instead, she told me to return to where I came from particularly after noticing I have developed fistula…I walked the 10 miles and my father very mad with me for going to him after I have developed fistula. He attributed the fistula to curse. He was of the conviction that somebody I might have offended somewhere might have cursed me with fistula…my father peripherally agreed to forgive me. Immediately the neighbors left he kicked me out of the house because he said I smell. (P06)

In summary, patients were stunned when close relatives, who they thought they could depend upon for support turned them away, sometimes leaving them exposed and in danger.

Theme 2: Women are Becoming Hardened, Bitter, and Hopeless

Patients experienced a loss of trust of others and a loss of hope that their situation could improve. They had difficulty believing in others again, particularly the men, family, and communities that had deserted them. Some had had multiple unsuccessful surgeries; for those, they lost faith in the healthcare system. Some felt that they had to learn forgiveness in order to wipe out the bitter feelings they harbored for those who abandoned them during their struggles. This was also a period during the Ebola epidemic, making it even more dangerous to have to travel and be exposed to many other people. Participants' responses included the following:

> I was always developing suicidal ideation because my death was better than my being alive with frustration and without love. (P09)
>
> Living with shame is devastating particularly when you are made the laughing stock in the community for thing you have no control over…Everyone in my community feared me for fear of infection…My brother allowed me to stay after begging with the advice that his children should not come near me and I should not use the cups they are using at home. (P11)
>
> From then I did nothing rather than sitting in one place and crying…Since nothing was done to help me, I, therefore, lost faith in the system and

> continue to hope to God…I would advise any woman to be careful with who they decide to live their lives because there is no true love or relationship (P01).
>
> I am still scared to come closer to people due to my bitter experience with them in my community (P3).

As these quotes illustrate, emotions remained scared, sad and bitter, with participants unwilling to trust or rely on others again.

Theme 3: Fistulas Can Lead Women to Depression and Emotional Distress

Understandably, patients became much stressed, and often so depressed as to entertain suicidal thoughts, and they allow themselves to become malnourished by eating and drinking less. Patients were haunted by the memories of their stillbirth with a deep sense of guilt for not doing much to prevent such an unfortunate event. Many felt they developed mental health problems, although this may be more accurately described as emotional problems. Some felt they were in a mental health crisis. Many traced this back to their experiences. Participants' responses included the following:

> When I developed the fistula my parents distance me because they believe that I developed the fistula due to my stubbornness…At first, I had no knowledge about fistula and I started crying…I fear living in the community due to leakage of urine and the odor it produced…I became depressed as I suffered isolation. (P02)

> I became depressed due to my belief that there was no cure for fistula…
>
> To some point, I preferred my death to living…From then on, I did
>
> nothing rather than sitting in one place and crying (P01).

Health problems such as obstetric fistulae are difficult to handle under the best of circumstances. However, presumably, had women been given hope of improvement in the future and/or had they been treated better by their families and communities, the incidence of depression would have been considerably smaller.

Theme 4: Financial Survival Became More Difficult During and After Treatment

Women feared to sustain themselves economically after being out of economic activity for a while, while they were treated and in recovery. Since the majority of patients are from rural areas, where hard work and/or farm work are the normal methods of income generation, medical advice not to engage in strenuous activities after surgery is usually ignored, as it would limit their financial activities. There are programs that teach them income-generation activities like soap making, weaving, and dying. Micro-financing can allow them to start up their own businesses when they return to their communities. In particular, the Haikal Care program in Bo, Southern Sierra Leone trains survivors in small-scale business. However, there are not enough other programs at the community level to help survivors manage on their own and support themselves. Participants' responses included the following:

> I was engaged in small gardening and carried the harvest to market and
>
> gave it to the market women for wholesale...If I stay too long my urine
>
> will leak and I will smell (P01).

> Since I had a stillbirth, I decided to sell the baby dressings and other materials I bought when I was pregnant so that I can pay my way to my mother... (P03).
>
> Desperately anxious to get well, I stole my father's fowl... (P2).
>
> I was discharged from the hospital and I went to the bush where we were rearing cows...to continue taking care of cows.... (P06).
>
> I started taking bread from the bakery and sell it. The profit was used to buy medication and clothes to cover the urine spills (P05).

Given their medical situation, women have increased needs for supplies, but have to make money any way they can in order to provide for all their needs.

Theme 5: Despite Challenges, Many Women Experienced the Work of Good Samaritans

On the other hand, there were some people who reached out to women in need and helped them when they needed it most. These people are remembered with love and gratitude while at the treatment center. Participants' responses included the following:

> One Ebola survivor...saw me groaning in pain and came to my aid.... (P01).
>
> I am very blessed that my aunt was proactive in ensuring that I am admitted... (P02).
>
> They all abandoned me except my aunt... (P04).
>
> At this time, my newly found friend... asked me to stay with her....

> But all my in-laws never abandoned me, particularly after the accidental death of my husband (P06).
>
> The attention I received from my mother's sisters brought great encouragement to me (P07).
>
> It was only my younger sister that continued to show love and concern for me (P09).
>
> My mother-in-law stayed with me (P11).

Fortunately for many of these women, someone, often a distant relative or someone who had been through a similar traumatic event, helped them with places to stay and access to treatment.

Theme 6: For Some, There Was a Fear of Toxic Gossip

The fear of gossip caused many women to change their behaviors and locations. Gossiping caused them to relocate to places they were not known and/or to places in the bush near water, where they could wash their urine-stained clothes out of sight of others. Participants' responses included the following:

> The news of my involvement in witchcraft quickly spread around the town and I went into isolation.... Since then, I remained indoors or at the back of the house for fear of gossip (P02).
>
> I became an instrument of community gossip orchestrated by even my former friends (P04).
>
> I kept silent about my health condition and did not discuss it with other people for fear of gossip.... (P06).

I never wanted to go to the hospital for fear of gossiping (P01).

Clearly, this was not harmless gossip and expressions of concern but very damaging rumors that women tried to avoid.

Theme 7: Some Women with Fistula were Miserably Affected by Paralysis and Foot Dragging

A frequent complication associated with the obstetric fistula was perceived paralysis particularly of the lower limbs, which led to foot-dragging, making the women even more outcast and making it even more difficult for them to access care. Participants' responses included the following:

> I was paralyzed in both legs by the time I was discharged. Being paralyzed I was just sitting in one place doing nothing to seek care. (P04).
>
> My feet became paralyzed and I lost control of my urine. I made no effort to seek care because I was paralyzed and my husband abandoned me and instantly married another woman (P05).
>
> Since I was paralyzed, I had nothing to do but remain indoors and do everything under me… Sometimes I crawl to the street and sympathizers gave me money which I use to buy pain medicine. (P11).

Clearly, not only were women isolated because of paralysis, but it also interfered with any possibility of receiving appropriate medical care when they were abandoned and had no way to get around.

Patients' experiences make it clear that much more can be done to prevent and treat obstetric fistula, as well as remove the mystery from it and make the condition more

acceptable to the community and provide resources for women who need extra assistance.

RQ3: What do patients of obstetric fistula perceive as barriers to medical care?

Obstetric fistula is both preventable and treatable, but patient participants in this study reported a number of barriers they experienced in seeking care. Patient's lack of awareness of their condition as well as treatment opportunities and resources prolong their suffering. The themes consistently observed from their responses are presented below (Figure 2).

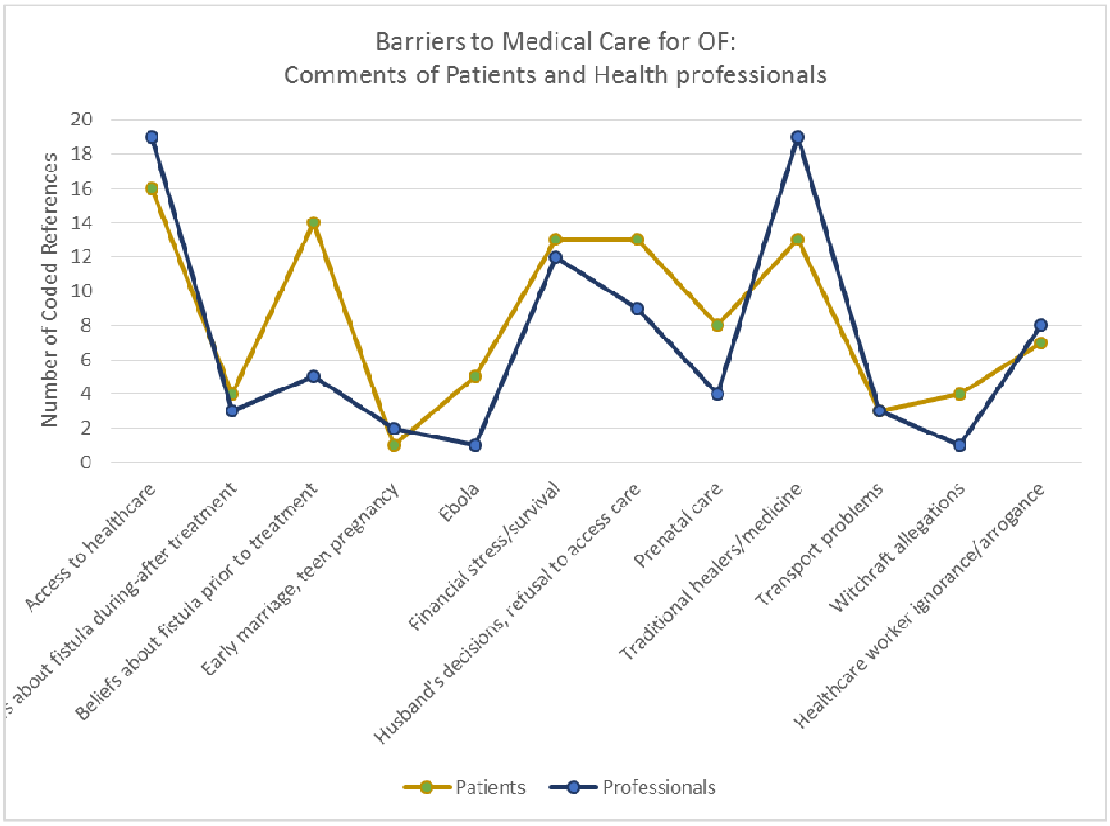

Figure 2. Barriers to medical care for OF

Theme 8: Many Women Experience Financial Barriers to Getting Medical Care

Men provided the financial resources and make health decisions for women. Women lack health decision-making authority, even for their own healthcare. Men are often slow to respond to women's emergency situations, particularly if they fear spending too much. There are also not enough facilities. Even when health services are available, the low financial power of women, many of whom live in poverty, prevents them from seeking care during pregnancy. Both men and women fear that hospitals will charge them huge amounts of money and that they may face high transportation costs to distant facilities, so they often do not seek medical care before, during, or after pregnancy. Men may try to send their wives to traditional birth attendant services, which may include home delivery rather than clinics because the home delivery services are cheap. Traditional birth attendants will accept payment in rice, yams, palm oil, or other edible or practical goods. Women also face the loss of income after pregnancies. Poverty among rural women is high.

Patient participants collectively reported being in a painful and protracted labor for at least three days at home without access to needed medical attention. The question which prompted participants' responses in this regard relates to barriers to medical care and focused narrowly on factors that hindered their health-seeking efforts. Almost all responses on this issue shed light on participants' inability to make health decisions due to their marital status and lack of money. Participants' responses included the following:

> I would have sought for care had I got money but my husband who pay my medical bill was not prepared to take me to hospital…. (P10).

> Lack of money and the unwillingness of my husband to take me to the hospital was a major problem. This even became worst after I started leaking…Information about fistula without money and the unwillingness of my husband to go to the hospital would have been meaningless. (P11)

> Even when I was in labor for 3 days he never took it serious….I was not by myself. I was with my husband who makes decision when to go to the hospital as he pays the bills. ……Even if the information was there about fistula I would not have been able to go to the hospital without the approval of my husband. (P01)

> The thing that prevented me from seeking care was my husband's unwillingness to allow me to visit the hospital….I never heard anyone talking about fistula before I develop it. Even if I heard the information, my husband was not willing to take me to the hospital for frequent check-up. (P07)

> The thing that might have prevented me from seeking care were lack of money and the failure of my husband to recognize emergency and agree to take me to hospital. (P03)

Often, women knew that their best chances for a good outcome from pregnancy and complications are admission to the hospital. But they faced barriers from having no

money for hospitals, or if their husbands had a little money, some men did not allow them to go to the hospital anyway. Clinics need to be free or low-cost and advertise widely as such.

Theme 9: Preference for Local Traditional Healers Serves as Barrier to Medical Care

Traditional medicine can have some merit relative to modern medicine, but it depends. There was no shortage of these informal providers who offered alternative sources of health care in the localities of patient participants. It is only the lack of options that caused patients to trust a provider or health system even when they do not measure up to expectations. There is now a campaign by health decision-makers to train more midwives, which will provide more access to treatment for maternal health challenges. The rural women in this study preferred home delivery to delivery in a health facility. They also trusted their traditional birth attendants more than they trusted nurses or doctors in clinics or hospitals. Fortunately, policy-makers are aware of the magnitude of the dangers of fistulae and preferences for traditional caregivers. That is why they have further encouraged the training of more traditional birth attendants in rural areas. The problem of fistula is worsened when birth attendants are untrained and unqualified to provide home deliveries. However, as noted, poverty and male health care decisions limit women's access to modern healthcare facilities. In addition, women see many women in their communities give birth to many children at home in the hands of traditional birth attendants and nothing bad happened that they have seen. Therefore, many women continue to see home delivery as a normal practice, citing the people they have known for

years who have given birth without complications. So either attitude must change: traditional birth attendants must be better trained and acquire qualifications for home births, or fistula will continue at a high rate. Women tend to believe that birth attendants understand their health problems better, and they feel closer to them. Also, some women are reluctant to expose themselves to doctors and medical personnel, not wanting them to see their nakedness. They see traditional birth attendants as more respectful.

Some have been told by their modern healthcare providers that there is no cure for fistula. They then seek healthcare from traditional healers. The healers usually end up exposing women to excruciating pain, still without healing them. Participants' experiences are demonstrated in the following quotes:

> I was taken to one traditional healer who started smoking me with boiled herbs. This could not stop my urine and I became frustrated, lost hope, and went into isolation as I continuously leak and smell (P01).

> I was discharged from the hospital and I was taken to traditional healers in Port Loko. During this time I was made to sit in warmed water filled with herbs and also covered with blanket to be smoked with the herb. This could not help me (P03).

> Most of our relatives gave birth at home and used traditional medicines throughout their pregnancies and nothing bad happened (P04).

> A neighbor who overheard my father intervened by telling him that he understood my health condition as a traditional healer and that he can cure me. He instantly went into the bush and gathered a lot of traditional herbs, boiled them and started smoking me with herb under the blanket. I was also given the liquid from the boiled herb to drink. The more I subjected to the heat from the herb and drinking the liquid, the more my condition was getting worst. Over 4 months of unsuccessful treatment, I lost hope in traditional medicine. Traditional healers were the first line of hope but when they failed to cure me, I finally believed that there is no cure for fistula (P06).

> Later I started warming water and adding salt to it. I sat in the warmed water several times a day. This continued uncured and I was finally brought to Aberdeen Women Center for surgery (P08).

Theme 10: Lack of Awareness about Fistula and Treatment Options Prevented Patients from Seeking Care

Knowledge is power. All fistula patients repeatedly indicated their total lack of knowledge about fistula. From the onset they had no idea as to whether their fistula can be treated or treatment options available. They were further misinformed by health professionals who persistently told them that fistula has no cure. Lack of knowledge of fistula gave way to societal accusation of witchcraft and curse as excuse for the disease. Believing that their fistula is the will of God, patients were unlikely to be interested in

seeking needed medical care at health facility. The following quotes demonstrate how the lack of knowledge served as barrier to medical care:

> I was in serious pain after the stillbirth and while I was hoping for medical attention, my husband's relatives and some of mine accused me of witchcraft. They took me to women society bush to force me to confess that I am involve in witchcraft. I received several hash lashes form the society women just for me to confess. The beating did not cause me to confess and they abandoned me in the society bush. (P03)
>
> My father later allowed me to stay at his house with the advice that his children should not come near me and I should not use the cups they are using at home for fear of fistula transmission. (P11)
>
> Since I was told by the nurses in the hospital that there was no cure for my fistula, I made no further effort to seek medical care. Everybody in my community feared me for fear of infection. (P10).

Theme 11: Modern Healthcare Workers Display Ignorance and Arrogance

Patient participants in this study collectively expressed great frustration and disappointment in the overall healthcare system. Institutional trust is crucial to health service utilization. Patients visit health facilities with the mounting expectation that providers are compassionate, capable, and empathetic to their health miseries. Anything contrary to such expectations can result in mounting frustration and distrust. Memories of previous negative patient-provider encounter weighed heavily in future health decision-making as patients are keen to the verbal and non-verbal expressions of care providers

and displays of medical competence. In this case, these patients' confidence that the health system could meet their needs was shattered the very moment their fistula was discovered, as the healthcare workers unprofessionally pronounced the patient's health condition incurable. Being discharged without achieving their health goals sent a wrong signal about the health system that eventually sowed the seed of distrust and acted as a barrier to further care.

Patient participants collectively disliked the attitude of healthcare workers. They were embarrassed by healthcare workers, as patients were considered dirty, unclean, particularly during pregnancy and after developing a fistula. Some nurses even openly told patients that they need to clean themselves up before coming to the hospital. This prevented some women from seeking further care, preferring to be treated at home. They also noted that even when they did make their way to modern healthcare facilities, they often experienced a lack of prompt and appropriate attention. They had a variety of unpleasant experiences in the hospitals. Some women tried a different healthcare facility for their next birth, but then those facilities were not familiar with their healthcare record and history of fistula. They, therefore, encouraged another vaginal birth, and the women ended up experiencing another fistula again. Otherwise, they tried traditional healers, who as noted above, do not cure them either, but exposed them to noxious herbs or heat or other painful treatments. The following responses serve as a clear testament to a patient's distrust of the healthcare system, a distrust that ultimately deterred their health seeking impulses:

> The doctor tried to draw the child from my stomach and they partially succeeded but the head of the dead child stuck inside me. Unable to draw the stocked head, they stopped the process and promised to continue the next day since it was night and the rest of the dead child's body was out while the head remain inside me. I was not in coma when this process was going on and the pain was too much for me…….. When I developed fistula while in the hospital initially I thought the nurses were very sympathetic of my plight but they started hiding from me. (P03)
>
> Haven been discharged from the hospital going home with both paralysis and incontinent, I was discouraged when the nurse advised me to bear with the condition as there was no cure for fistula. I was taken to another hospital in my town and other nurse told me the same thing that there is no cure for fistula. (P05)
>
> When I had the fistula, I frequently visited the Port Loko hospital for cure but I was always told that there is no cure for fistula (P07)

Clearly, traditional healers are not the only ones who need better training; modern healers need training too. It may be that because patients are poor, wages are low so that the best nurses and doctors tend not to practice in these areas. But in many cases, patients are not being respected and properly cared for when they do go to the hospital.

Theme 12: Fear of Ebola Prevented Some Women with Fistula from Seeking Medical Care

The outbreak of Ebola in Sierra Leone had a damaging effect on health and health services in the country. Among countries in the world with the weakest health system, Sierra Leone's Ebola crisis led to the closure of key health facilities while the majority

was converted into Ebola treatment units. Most of the facilities converted into treatment units eventually became the centers of disease transmission. This caused attendance at health facilities in general to decrease drastically as the fear of Ebola contraction loomed with the death of health workers. Even facilities offering basic emergency obstetric care saw a dramatic decrease in facility-based deliveries and postnatal care as well as family-planning services. This drop of health services utilization increased the risk of OF cases for women of childbearing age. Since most Ebola victims contracted the virus in health facilities, patient participants collectively reported their reluctance to seek care in health facilities. This is vividly expressed in the responses as indicated below:

> Unfortunately, my fistula developed at the height of the Ebola crisis and all the medical experts left the country…the Ebola scared me from visiting the hospital since most victims contracted the virus in the hospital. When I attempted to seek care, hospitals were not ready to accommodate me and I had to live with the fistula. (P03)
>
> I develop fistula at the height of the Ebola crisis and going to the hospital for care was not an option for me because of fear of being considered an Ebola patient …patients were rejected admission in the hospitals at that time…when I was in labor, I was barely accepted in the hospital when they found out that the baby has died in my stomach… I tried to visit several health centers but I was rejected because of the Ebola. I was told to wait till the Ebola is over since expatriates in the hospitals fled the country. I went home and constantly pray for the Ebola to be over. (P02)

Nurse Interviews

In addition to investigating the experiences of patients with obstetric fistula, this study investigated the understanding of medical personnel regarding their patients' experiences of obstetric fistula. Two research questions were posed:

RQ2: What are the experiences of obstetric fistula as perceived by medical personnel attending obstetric fistula patients?

RQ4: What do medical personnel attending obstetric fistula patients perceive as barriers to medical care?

The responses were examined separately for the nurses versus the surgeons in the study, and the themes that emerged are illustrated in Table 4. The responses from nurses will be examined in detail first.

RQ2a: What are the experiences of obstetric fistula as perceived by nurses attending obstetric fistula patients?

Nurses were well aware of many of the experiences experienced by survivors of obstetric fistula. They cited the following themes when discussing the challenges facing survivors. They cited each of these challenges to different degrees, and the interview process did not ask which of these challenges were greater than the others, although all were cited by all nurses as being great challenges faced by survivors of fistula. Some made lists of challenges without further comment. Where available, representative comments from the nurses are detailed below (Table 4).

Theme 13: Divorce or Separation Is One of the Most Dehumanizing Experiences of Some Women with Fistula

Men often do not want to deal with a woman with obstetric fistula and will force her to leave. Other women may not want to return to their men even after a fistula repair, because of how they were treated. A comment from one nurse is below.

> Some survivors may prefer to look for a new relationship after they return to their community because of the embarrassments and abandonment they suffered at the hands of their husbands (N04).

Theme14: Abandonment and Ostracism by Family and Community Is One Major Social Experience that is Impossible to Erase

Through no fault of their own, women with obstetric fistula can be unpleasant to be around because of the smell. In addition, there are fears associated with obstetric fistula, such as that it is associated with witchcraft. Therefore, many women are abandoned. Their families and their communities want them to leave. A few representative comments from the nurses' responses are listed below.

> Being an outcast is a major concern for fistula patients, as their family and community fails to understand their predicament and associates them with witchcraft (N01).
>
> Fistula reduces women to isolation as they are prevented from associating with other women due to their urine odor. They are prevented from participation in their religious practices, which are normally done in a group as a community (N04).
>
> They have no sense of belonging since they consider themselves as societal outcasts (N05).

Theme 15: Fistula is a Highly Stigmatized Condition and Affected Women Suffer Accusations of Witchcraft

Many rural societies do not consider obstetric fistula to be a normal complication of childbirth, but rather an indication of evil or witchcraft. The nurses understand that the women are shamed in their villages and may lose self-esteem. A few representative comments from the nurses' responses are listed below.

> Stigmatization and fear that their reintegration into society after their vaginal repair will be impossible, as their health condition was viewed by them as a mark of witchcraft (N01).
>
> Lack of community knowledge about fistula causes more suffering for patients of such health condition.... She was abandoned by her husband and family as she was accused of practicing witchcraft (N04).
>
> Fistula is still associated with witchcraft rather than a maternal health problem that is preventable (N06).

Theme 16: The Economic Burden Posed by Fistula Erodes Women's Self-Esteem

Fistula develops after long periods of labor, which also leads to the women needing time off from work followed by light duty. However, economic realities often make this impossible. A few representative comments from the nurses' responses are listed below.

> They have fear of sustaining themselves economically after being out of economic activity for a while (N01).

> Since the majority of fistula patients are from the rural areas, where hard work or farm work is the order of the day for income generation, the advice not to engage in hard work after surgery is usually ignored, as it limits their financial activities (N04).
>
> Absence of income generation ability and begging for survival (N06).

Theme 17: Some Women with Fistula Suffer Homelessness and Hunger

Naturally, as women with obstetric fistula are abandoned by their families and communities, finding a new home is a problem for many. Some end up living in the bush. One nurse's comment is listed below. Again, some simply listed homelessness as a problem, without commenting further.

> There is also the fear of getting a place to live particularly when the perception of the society and family is still negative. They are considered as outcasts with no family due to their health condition (N01).

Theme 18: Obstetric Fistula Affects the Physical Well-Being of Women

In addition to obstetric fistula, several nurses mentioned paralysis/foot dragging as a complication. A difficult delivery also might result in a stillbirth. Nurse 2 also added the comment below.

> Dehydration: They believe that drinking water leads to frequent urination and since they can't control their urine, they are reluctant to drink. Lack of drinking water causes their urine to be highly concentrated and they end up developing bladder stones, which also can destroy their bladder (N02).

Theme 19: Mental Health Issues are a Result

The stress of obstetric fistula takes a toll on women's mental and emotional health. Issues include depression and suicidal ideation. A few representative comments from the nurses' responses are listed below.

> Being outcast causes huge frustration and mental health problems for them (N01).
>
> Their belief before their fistula repair that they are the only one with such health condition makes them develop suicidal ideation (N02).

Theme 20: Embarrassment Means that Women Do not Seek Treatment

A natural experience of obstetric fistula in an area with few laundry facilities is odor. This and the resulting gossip, shames and embarrasses women so that they prefer to stay by themselves. Some even feel the need to leave the town. A few representative comments from the nurses' responses are listed below.

> They lack social connection due to their urine leakage and offensive odor (N01).
>
> Gossiping causes them to relocate to places where they are not known (N02).

Theme 21: Many Women Have Difficulty Reintegrating into Society

Nurses were asked the types of community and social services available for assisting women with reintegration into society after successful repair of obstetric fistula. All nurses related that the only source is located in Bo, in the Southern Province at Haikal, where rehabilitative services are provided. Included in the rehabilitative services is training for survivors in trades such as soap making, and micro-business training.

These women are provided with encouragement to return to their own communities and reintegrate into society. Women are additionally reported to be provided with micro-financing to start their own businesses. Included in the rehabilitative training services, as well, are the needlework trade and adult literacy. Financial management courses and training are also provided. Prior to the Ebola crisis, there was a free 555 phone line for women with obstetric fistula. In addition, women in the program learn about forgiveness, in hopes that they may be able to wipe out bitter feelings that they harbor for those who abandoned them due to their obstetric fistula. This program has been very successful, but there are not enough programs to service the large number of women in need. A comment from one of the nurses is detailed below.

> Haikal Care in Bo provides training or rehabilitation programs for fistula survivors after surgery. They are taught income generation activities like soap making. They are also given micro-finances to start up their own businesses when they return to their communities (N02).

Additional Information: Nurses' Views of the Future and Final Thoughts

When nurses were asked if they thought that obstetric fistula will continue to be a problem in Sierra Leone, the answers included the following themes:

Theme 22: Obstetric Fistula Will Continue to be a Problem

Many of the nurses believed that conditions will not change soon. Their concerns included a continued lack of access to medical care during pregnancy, including cesarean sections (which are often performed to prevent risk of obstetric fistula); continued use of inadequately trained and unqualified traditional birth attendants; failure of women to

follow medical advice; early marriages and pregnancies while very young; reluctance to admit to medical problems and seek health care for fear of, for example, being labeled a witch.

N03 exemplified the answers of the nurses, most of whom provided several answers similar to the above. The following was her response:

> Yes, the stubbornness of survivors to follow discharge instructions by failing to return to the fistula center for delivery following pregnancies and their continuous use of TBAs [traditional birth attendants] will lead to the development of fistula again. Also, survivors going to other health facilities not familiar with their health condition and have a vaginal birth may develop fistula again. Ignorance on the part of the public causes suffering for women, and men who are breadwinners and who make decisions about health insist on TBAs because they are less expensive. Many women continue to view home delivery as the normal practice, and unless there is a change of attitude toward home delivery under the untrained and unqualified traditional birth attendants, fistula will continue to prevail (N03).

Theme 23: Hope for Change So Obstetric Fistula Will not Continue to Be a Problem

Nurses were asked if they thought that the experiences of obstetric fistula are well enough recognized by health policy-makers to improve women's access to care and whether they are well enough known to help highlight the need for maternal care in Sierra Leone. The nurses believed that opportunities were increasing and opinions were

gradually changing. They hoped that radio and television public service announcements were increasing awareness. They knew that traditional birth attendants were receiving better training. They suggested that increased resources be spent to provide more facilities to be within affordable reach of more women. Nurses' responses included the following:

> Policy-makers are quite aware of the magnitude of fistula that is why they have stepped further to encourage the training of more traditional birth attendants (TBA) in the rural areas. The NGOs are more vigilant in achieving this goal than the government (N01).
>
> Since most of the patients of fistula are students, they should be encouraged to return to school after repair and recovery. The fistula repair facility should be extended to the rural areas since transporting patients from the villages and maintaining them before surgery is expensive (N04).

Theme 24: Final Thoughts

Finally, when nurses were asked if there was any other information that they believed was important to know about obstetric fistula that might help in better understanding this issue, two nurses in this study gave the following responses:

> Fistula is real, it is causing mental health problems for rural women. The traditional belief that fistula is a curse is killing women. The pain and trauma they undergo are too much. We need to double up our efforts to minimize its occurrence (N01).

> Exposure to mosquitoes can cause anemia that in turn leads to preterm labor. Some women who are supplied with mosquito nets tear them into pieces for bathing, dish washing, trap setting, or covering their crops to prevent pests from destroying them (N02).

As can be seen from the above, patients have many issues affecting their ability to seek proper obstetric/gynecological treatment for pregnancy, labor and delivery, and obstetric fistula and other complications, as well as dealing with a range of serious adverse experiences from developing an obstetric fistula. However, nurses who provide professional care for such women have significant, deep understanding and empathy for their problems.

RQ4a: What do nurses attending obstetric fistula patients perceive as barriers to medical care?

In interviews with nurses, several questions were asked to elicit nurses' understanding of barriers to medical care for obstetric fistula patients. These questions elicited several common themes recognized by most of the nurses. Each theme will be examined individually below and supported by direct quotes from the nurses where available (Table 5).

Theme 25: Patients Were Challenged by Long Distances Between Facilities

According to the nurses, health facilities that specialize in the treatment and rehabilitation of patients with obstetric fistula include the Aberdeen Women's Center and one other, Haikal in the city of Bo, in the Southern Province. The Haikal facility provides more services, but the surgeons are not permanent in that facility. Rather, they

occasionally visit Sierra Leone from the United States of America to perform surgeries, and then return home. Transportation can be difficult to the few remote facilities. A few representative comments from the nurses' responses are listed below.

> Most women of childbearing age live in remote corners of the country that have no paved roads for vehicles to run through. Even where vehicles can ply the routes, distance to the health facility is also a factor (N04).
>
> The few gynecologists that are qualified prefer to stay in the city while the rural areas go without (N06).

Theme 26: There Was a Severe Lack of Awareness Amongst Women

The nurses described the present state of awareness of obstetric fistula and its prevalence among women in Sierra Leona as abysmally low among NGOs and policy-makers, resulting in too little concern among health planners and non-governmental organizations. Awareness of obstetric fistula is also low among the rural population. Radio and television media are the focus of public awareness campaigns, but in rural areas there is little or no access to radio or television. NGOs and government agencies appear unaware that this information is not reaching rural areas. In addition, health care decision-makers are not allocating the necessary funding and resources to address this problem. A few representative comments from the nurses' responses are listed below.

> The awareness level of fistula is high only in the cities where media outlets are in abundance as opposed to the rural areas with little or no such facilities. Medical doctors conduct public awareness campaigns through

> the radio station and the TV. In the provinces or rural areas, fistula patients think they are the only ones with such health condition (N01).
>
> News of frequent deaths in the health facilities during the Ebola epidemic scared them from going to the hospital (N02).
>
> There is lack of knowledge of the experiences to be expected for not going to the hospital during pregnancy (N03).

Theme 27: Young Teenage Mothers Are at Risk

The nurses recognize that the risk of obstetric fistula is increased in teenage pregnancies. Underdeveloped bodies are more likely to experience pressure during labor and delivery, making fistula more likely. Underdeveloped bodies may also lengthen the time that a mother is in labor, a second risk factor for fistula. Young teens are also much less likely to seek medical treatment and receive prenatal care. They may be afraid to let others know that they are pregnant, so may hesitate until late in the pregnancy. Most nurses listed teen pregnancies without further elaboration, but Nurse 6 commented:

> There is a serious concern over teen pregnancy in Sierra Leone, which is the root cause of fistula (N06).

Theme 28: Some Women are Unable to Seek Out or Travel to Treatment Centers Due to Financial Constraints

Nurses stated that financial reasons that women may not seek appropriate maternity and prenatal care included poverty and the fear of high charges. They were aware that rural women trust traditional birth attendants, who are often known to women and thus more trusted than hospital personnel, but who are also significantly cheaper than

hospital visits. Another cost, given that there are only a few remote facilities, is the high cost of transportation to healthcare facilities, along with costs of living for a family who may want to attend the birth. A few representative comments from the nurses' responses are listed below.

> Poverty among rural women is high and the fear of being charged by the hospital or clinic in case they visit during their pregnancy prevents them from seeking appropriate maternal care (N04).
>
> Since women lack health decision-making authority and are too poor to pay for services, they are always afraid to go to the clinic during pregnancy with the fear that they will be heavily charged for services. They prefer going to their traditional birth attendants, who are willing to accept anything for services delivered like rice, yams, palm oil, etc. (N05).
>
> The financial reasons that prevent women from seeking maternal care range from high transportation costs since most stay far away from health facilities and the fear of being charged heavily while in the hospital (N06).

Theme 29: Some Women are Embarrassed to Expose Their Body to Strangers and Their Inability to Control Their Urine

Two sources of embarrassment are being examined by strangers, particularly male doctors, and being rejected because of smelling unclean due to urine leakage. A few representative comments from the nurses' responses are listed below.

> Another thing is the attitude of healthcare workers as they normally view the patients as dirty. The women don't want to be embarrassed. As such, they decide to give birth at home (N02).
>
> They suffer embarrassment from urine odor. This prevents them from boarding public transportation to seek health care (N04).
>
> Some women do not feel comfortable for doctors or medical personnel to see their nakedness. They prefer to meet with their traditional birth attendants who they consider to be cheap and respectful. Some women hate the arrogant attitude of healthcare workers as they refer to visiting patients or pregnant women as dirty and openly announce that they should make sure that they clean before coming to the hospital (N05).

Theme 30: Belief in Traditional Medicine Can Act as a Barrier that Affects Women's Decision to Seek Care

Traditional medicine includes birth attendants, natural delivery, and herbal remedies. The nurses understand that women believe that traditional medicine will be safe and effective; but even when they are unsure, they may not have the money for a hospital but can make payment arrangements with their Traditional Birth Attendants (TBA). A few representative comments from the nurses' responses are listed below.

> Some believe that many women in their communities have given birth to many children at home in the hands of traditional birth attendants and nothing bad happened (N02).

> Many women prefer their traditional birth attendants, who are closer to them and better understand their culture. They also prefer home delivery where they are not subjected to nurses' molestations (N03).
>
> Many women prefer to stay connected with their traditional birth attendants who are normally older women in the community with great knowledge in herbs (N06).

Theme 31: Pressure from the Traditional Patriarchal Society Prevents Women from Accessing Health Care

In most households, the husband is the sole decision-maker in what expenditures will be covered by limited funds, including healthcare expenditures. Most women have no money of their own to pay for their healthcare needs, in addition to no decision-making power about their own healthcare. A few representative comments from the nurses' responses are listed below.

> Even if the needed health services are available, which in most cases they are not, the low financial power of women prevent them from seeking care during pregnancy (N01).
>
> Women's lack of health decision-making power is due to poverty and over-submissiveness to husbands (N04).
>
> The husbands, who are the sole breadwinners of the family, decide when it is necessary for their women to visit the hospital since they foot the bills. Men reserve the health decision power for the family (N06).

Fistula Surgeon (FS) Interviews

The final portion of this research was dedicated to understanding the views of fistula surgeons. The same two questions were posed to the surgeons as to the nurses: What are the experiences of obstetric fistula as perceived by medical personnel attending obstetric fistula patients? What do medical personnel attending obstetric fistula patients perceive as barriers to medical care? Several themes were identified from this research.

RQ2b: What are the experiences of obstetric fistula as perceived by fistula surgeons attending obstetric fistula patients?

Theme 32: Obstetric Fistula Can Lead to Women Having Severe Mental Health Problems

Like the nurses, the physicians felt that the experiences of having an obstetric fistula were diverse and depended on the individual case, but that mental health problems amongst these women were common. One physician noted that:

> The stress of having to give birth, coupled with accusations of witchcraft and the associated stigma, put together with shame and incontinence problems, means that many of these women have mental health problems associated with their condition. In some cases, these will improve after surgery, but for others, the stress of the whole situation makes this much harder to treat. It is important that we understand the complications of fistula for these women and their psychological health as well as their physical health (FS02).

Like the nurses, the physicians also felt that less attention was paid to the psychological experiences of fistula than to the direct physical issues. This can be a problem because:

> Psychological issues are generally much harder to treat and can lead to further accusations of witchcraft, which makes the problem worse. I am a surgeon and therefore do not focus on mental health issues, but it is something that I see time and time again (FS01).

> Some patients without a support network can deal with the surgery or the fistula very badly. They can be abandoned by their husband and their friends, which means that they have no one to turn to, no advice to receive. This can make the whole situation much, much worse than it needs to be and is something that needs to be dealt with (FS02).

Overall, psychological issues were a major concern for the physicians as for the nurses, as it can compromise the ability of the patient to heal after the surgery and makes life more difficult in terms of finances and repairing relationships that may have broken down due to the fistula.

Theme 33: Women Can Be Abandoned by Family, Friends, and Their Community

This is one of the most serious problems identified by the physicians. Although they do less patient communication than the nurses, this issue was so obvious that all of the participants noted it and mentioned it as part of the interviews. The physicians felt that:

> Women deal with a lot of stigma and stress as a result of fistula, and this can lead to them being abandoned by their husbands and friends. This is largely due to two factors. The first is that the smell from urinary incontinence puts people off, although the women themselves cannot help it and it is not abnormal in these cases. The second is that people do not want to be associated with someone who is sick, or who has been accused of witchcraft, as this has an impact on their own social standing (FS02).
>
> Although many of the women that come for surgery are not on their own – they generally come with a mother or an older female relative – many of them do come on their own. They do not come with their husbands, who associate the fistula with some negativity, and I have met many patients who have been abandoned (FS01).

As mentioned previously, this abandonment can lead to the worsening of mental health problems and means that women are less likely to seek treatment. All of these factors link together in some way and become a vicious cycle:

> Women are scared to come in to seek treatment because they are scared of being found out. They are then found out, and scared to seek treatment because they have to come alone. This then makes the problem worse, and they are ostracized further. This makes dealing with fistula in this country very difficult and different in Western nations. There needs to be some discussion of support groups for these women so that abandonment does not become such a big issue that it stops them from seeking treatment (FS02).

Theme 34: Women May Lose Financial Support After Diagnosis

As mentioned above, financial issues tie in directly with some of the challenges that physicians have in treating women for fistula. Traditional medicines are preferred for many reasons, but one of them is that women do not have to stop caring for their children or working during it. A surgery may mean that they have to be careful and recover more slowly, which means a loss of financial support or income. One physician notes:

> Not only do patients have the problem of getting money for the treatment and perhaps losing the financial support of their husband, they are also faced with possibly losing the ability to work or look after their children for a few days. In the cases where this happens, it can be very difficult for women to have the recovery period that she needs (FS02).

The physicians felt that financial issues were less important than some of the other issues associated with getting treatment, as they were not as personally affected by it as nurses and the patients themselves. Despite this, it is clearly important to understand the limits of physicians when coming to terms with all of the different barriers and experiences that these patients face and how best to deal with the issue and promote safer, more effective treatments.

RQ4b: What do fistula surgeons attending obstetric fistula patients perceive as barriers to medical care?

Theme 35: Women Do Not Have the Financial Resources to Seek Help from Medical Professionals

Many of the surgeons felt that women were not seeking surgery for their fistula because of financial constraints. Women who overcame the other boundaries to care and sought assistance from nurses were still unable to complete surgical treatment, largely due to financial constraints. The two physicians in the study stated that:

> Speaking to the nurses, it is obvious that there are many different patients who need my help, but cannot afford to go through to the surgical stage. This leads to other problems with alienation and mental health problems because they are aware that something is wrong but feel powerless to change it (FS02).
>
> I am aware that I cannot give away my services for free, and this is a barrier to many of the women that might need surgery for obstetric fistula. Some of these women desperately need help to be able to live a normal life again, but cannot because of the cost (FS03).

This was one of the problems that was identified by the nurses. The major barrier to care appears to be that women simply cannot access the services due to the financial constraints placed on them. This problem may be worsened if the fistula has led to them being alienated from their friends and family who may otherwise be a source of financial help.

Theme 36: Women are Embarrassed to Seek Treatment from Doctors for Obstetric Fistula

The surgeons, like the nurses, noted that embarrassment was a key reason why women were not seeking help for their condition. The surgeons felt that the nature of the condition led women to being shamed inside their communities, which in turn had an

effect on their willingness to seek help. Two doctors felt that they tried their best to reassure women that their records would be confidential and that their condition was not unique:

> The best I can do is to make a woman feel comfortable with the surgery and the aftercare, but if she is receiving negativity from outside, I cannot do anything about this and that limits the women's willingness to seek treatment (FS01).
>
> Fistula is not an uncommon problem and it is something that I have treated many times. This should be a reason why women feel more comfortable coming in for the surgery, but there is still a stigma for women seeking this treatment that will not go away (FS02).

Again, this marks itself out as being one of the major reasons why women cannot seek treatment. Nurses, physicians, and the patients themselves noted that there was a sense of embarrassment and stigma associated with this condition which was limiting women in their search for treatment. Without a support network, this embarrassment was much stronger:

> I have seen women come in with family members and they are usually much more willing to talk to me about their problems and go through the surgery. I think a social support system helps, but not every woman has that and they continue to be embarrassed about seeking care (FS01).

Overall, embarrassment or shame is a key problem for women seeking treatment.

Theme 37: Stigma Is a Real Issue for Women Seeking Treatment

Similarly, stigma contributes to the embarrassment that these women feel when seeking healthcare. Like the nurses, the physicians' interviews here also identified accusations of witchcraft as one of the potential reasons why women do not seek treatment:

> I have seen women say that they are worried about people finding out about their treatment and surgery. I am worried that the association of women with witchcraft means that they are not seeking the vital healthcare treatment that they need, and this means that they are putting themselves in danger (FS02).

This stigma is a very real issue because it affects women even after they have received treatment. One physician notes:

> I have to be very careful to reassure these women that their information is secure and that I will try my best to make sure that it does not leak into the community. This does not always work due to the tight relationships between these women and their families, but it is the best I can do (FS01).

It is unfortunate that this health condition is associated with witchcraft and significant amounts of stigma, even after women have undergone surgery. It was also noted by the physicians that women felt uncomfortable undergoing the surgery because they felt that they would be permanently marked by it – again, something that is associated with witchcraft and traditional belief systems.

Theme 38: There Is Still a Heavy Reliance on Traditional Medicine that Can Make Women Wary of Seeking Surgical Treatment

The physicians felt that sometimes women were very uneasy about having surgery. This is normal in many cases, as surgery for obstetric fistula is a serious thing, but the physicians felt that it was a reliance on traditional forms of medicine that made surgery more intimidating and led to women having reservations about the procedure. One physician noted:

> Women do ask me if I am able to help them in some other way, something more similar to the herbal treatments that they have already been using. In most cases, this type of treatment is not doing the women any harm, but the surgery is better. It can be a challenge to reassure patients that the fistula surgery is a much safer and more effective way of dealing with the issue. I think beliefs in traditional forms of medicine are very important, but it can be a real challenge trying to reassure these women (FS03).

It was also noted that beliefs in traditional medicine can interfere with the post-surgical recommendations. It was noted that:

> We obviously have certain things that we prefer women to do after surgery, such as staying restful and making sure they take antibiotic medication to prevent infection, but this largely goes ignored when women want to use their own systems for treatment. Again, this can be a real barrier to getting women to have the surgery and to continue with follow up advice (FS01).
>
> I have noticed that women do not always want to follow proper aftercare solutions. This can be a major barrier to the surgery as I do not want to perform it if the woman is going to be in danger afterwards (FS02).

These results are very similar to those found amongst the nurse participants in this study, who also felt that traditional medicine can be a limiting factor.

Summary

The data analyzed in this study were derived from interviews with twelve patients who have experienced obstetric fistula, six nurses who have been involved in fistula care and two fistula surgeons. All the patients in this sample were women who were in labor at least three days at home prior to coming to the hospital and had a stillborn child prior to developing a fistula. All of the patient participants in the study had fistula due to urine leakage. None of them had been informed prior to urine leakage that this condition might possibly exist and, most shocking, many of the patient participants had been informed by hospital healthcare workers that there was no cure for obstetric fistula, and had been discharged and sent home. The result of this misinformation was that many of the patient participants sought out traditional healers for the obstetric fistula, who performed herb smoking and other traditional healing methods that were unsuccessful, resulting in patients losing hope.

Experiences of Obstetric Fistula

Women's experiences of fistula were very much related to these barriers, and many were confirmed by the medical personnel interviewed for this study. The data are clustered into themes of prevalence of OF, physical harm, financial harm, emotional harm, social harm, and traditional expectations and beliefs.

Prevalence of OF. All patients had fistula due to urine leakage. They were all from remote, rural areas, and fistula services are in urban centers which are difficult to

access due to costly transportation. The very young age of many new mothers increases their risk of OF.

Physical harm experienced by patients. Fistula causes urinary tract infections, nerve damage, and kidney failure. Several women experienced foot dragging and lower-level paralysis. Some patients experienced extreme pain and distress.

Financial harm to patients. Women experienced a loss of income, due to loss of work time and stigma. For some women, this reached the point of homelessness and starvation. Women were not able to take the time off that they needed to heal from surgery. Doctors expressed concern about this and how it affected women even after they had undergone surgery.

Emotional harm experienced by patients. Women with fistula tend to become hardened, feeling bitter and hopeless. Their self-esteem suffers. Medical personnel recognized mental health as patients experienced emotional distress to the point of depression.

Social harm to patients. All participants felt that abandonment was an issue. They were often deserted and/or shunned, driven out of their homes. All felt that they did not have a strong support system in place to help them get through. They experienced ostracism from their communities. Because of this, they feared toxic gossip, such as belief that their conditions involved witchcraft. Women who survived usually felt that it was due to a good Samaritans, often distant relatives.

Traditional expectations and beliefs. Women often survive childbirth without complication with the help of traditional healers. They therefore began with trust in

traditional healers and felt they provided emotional support while medical personnel often seemed distant and arrogant. Despite 'treatment" for fistula that did not work, these women trusted traditional approaches. Some women were wary of surgical treatment.

Barriers to Care

The patients, nurses, and physicians all had similar views about the barriers that are facing women with obstetric fistula. These can be clustered into themes dealing with financial barriers, social and emotional barriers, traditional healers as barriers, and medical staff poorly trained and patients unaware of options.

Financial barriers. None of these fistula patients had adequate money to afford medical treatment. Men are reported to have control of the money and thinking treatment is unnecessary. Even when surgery was available, transportation was very costly and inaccessible. Patients suffered loss of work and family support when fistula became known.

Social and emotional barriers. Stigma, accusation of witchcraft, abandonment/ostracism and a patriarchal society all distracted women from accessing healthcare. Other deterrents were dislike of medical personnel as a result of bad experiences in the past, and fear of Ebola at the hospital.

Traditional healers as barriers to care. There is easy accessibility of local healers. Medical staff seen as distant and arrogant; healers give emotional support; and beliefs that women's bodies should not be exposed to unrelated medical men. Traditional treatments such as herb smoking not successful but women still trust them.

Poorly informed medical staff as a barrier to effective medical care. Medical staff had little knowledge of OF prevention or treatment. Patients were not informed prior to leakage that fistula might happen. They were also wrongly informed by medical staff that there is no cure for OF. Patients lacked awareness about medical options for treatment.

The findings in the study following analysis of the data reveal that nurse workers in hospitals and clinics are not providing women with the information needed to avoid developing obstetric fistula. There appears to be little knowledge among hospital staff about obstetric fistula, since the women who had developed obstetric fistula were informed that there was no cure for this condition. Patient participants state that fistula is becoming more common in the area in which they live; however, this study did not determine whether these women believed this to be true based on the numbers of individuals with fistula prior to their development of fistula, since women were unaware of this condition until they developed it. What this study did ascertain however, is that fistula is not uncommon in Sierra Leone and most of the patient participants knew multiple other women who had fistula in the area in which they lived.

The Aberdeen Women Center in Freetown in the Western Area and the Haikal Fistula center in Bo in the Southern Province are both working to provide care, rehabilitation, and reintegration for women in Sierra Leone who experience obstetric fistula, as noted by the nurse participants in this study and the two fistula surgeon participants in this study. There is a great need for awareness campaigns in Sierra Leone to address the problem of obstetric fistula. However, as great as the need that is indicated

in this study's findings is the need to inform and educate health care workers in hospitals and clinics in Sierra Leone, as these individuals appear to believe that there is no cure for obstetric fistula and therefore are not providing the much needed information to women in Sierra Leone who are experiencing obstetric fistula.

These issues will be discussed in more detail in the next chapter, but here I highlight the fact that women face significant barriers to care and this has a negative effect on their abilities to deal with fistula.

The next chapter includes in detail the interpretation of the findings, limitations, recommendations, and potential impact to positive social change.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Despite medical advances, maternal morbidity and mortality in childbirth worldwide continue to be an extensive problem. Sierra Leone has the worst record for maternal mortality at 1100 deaths per 100,000 live births (WHO, 2014). In addition, a common complication is prolonged labor (up to several days) due to obstruction, which can cause OF (Meyer et al., 2007; Tebeu et al., 2012). This is more likely with home births, although competent midwives or birth assistants can lower this risk (Wall, 2012a; Warren & Mwangi, 2008). An estimated 3.5 million women worldwide suffer from obstetric fistula, most in sub-Saharan Africa and South Asia (Rai, 2011).

Obstetric fistula results in the leakage of urine and/or feces, which results in odor in communities where water for washing and/or sanitary pads and such supplies are difficult to obtain. This, in turn, often results in depression, ostracism, loss of family and work opportunities, and PTSD (Wall, 2012a). Other possible medical complications include urinary tract infections, nerve damage, and kidney failure (Wall et al., 2004). In rural communities where the cause and prospects for repair may be unknown, women are blamed and even vilified as witches (Adler et al., 2013).

Nature and Purpose of and Reason for the Study

The rates of both fistula and maternal/child deaths can be greatly diminished with proper care during childbirth. Where necessary, obstetric fistula can be treated with surgical repair (Wall, 2012a). Surgery, postoperative care, and rehabilitation only cost about $300 per person (UNPF, 2012). However, inadequate access to skilled care is

common where there are high levels of poverty, illiteracy, early pregnancies, and where women lack decision-making power over their own health (Zheng & Anderson, 2008). To better advocate for women in these countries, more data is needed to define the extent of the problem (Abouzahr, 2003). This phenomenological study of the experiences of women in Sierra Leone who live with obstetric fistulas provides that data. It shows risk factors and barriers that contribute to the delay in proper care for childbirth, and provides positive potential solutions for better maternal healthcare that will hopefully advance national policies and programs for the reduction and eventual elimination of obstetric fistula in Sierra Leone.

In this study, I addressed four research questions:

1) What are the experiences of obstetric fistula as perceived by patients?
2) What are the experiences of obstetric fistula as perceived by medical personnel attending obstetric fistula patients?
3) What do patients of obstetric fistula perceive as barriers to medical care?
4) What do medical personnel attending obstetric fistula patients perceive as barriers to medical care?

The study is based upon and supports two theoretical models: the AAAQ model (Echoka et al., 2014; PHR, 2010) and the three delays model (Thaddeus & Maine, 1994).

The AAAQ model states that healthcare should be assured with availability of healthcare infrastructure, within a physically and economically accessible zone, with cultural and ethnic acceptability, guided by at least adequate but preferably high levels of

medical quality (Pacaquella et al., 2012). The lack of application of the AAAQ model to healthcare during childbirth in Sierra Leone has led to the prominence of obstetric fistula.

The three delays model states that delays in individual decision-making, identification of and transportation to a health facility, and obtaining adequate care after arriving to a facility are closely interwoven barriers to care, and influence subsequent decision-making regarding seeking further care (Echoka et al., 2014). This model provides further insight into the actors and factors that result in the failure of healthcare decision-making to access emergency obstetric care.

Summary of Findings

The data I analyzed in this study were derived from interviews with 12 patients who have experienced obstetric fistula, six nurses who have been involved in fistula care, and two fistula surgeons. All the patients in this sample were women who were in labor at least 3 days at home prior to coming to the hospital, and who had a stillborn child prior to developing a fistula. All of the patient participants in the study had fistula that resulted in urine leakage. None of them had been informed prior to urine leakage that this condition might possibly exist and, most shocking, many of the patient participants had been informed by hospital healthcare workers that there was no cure for obstetric fistula and had been discharged and sent home. The result of this misinformation was that many of the patient participants sought out traditional healers for the obstetric fistula, who performed herb smoking and other traditional healing methods that were unsuccessful, resulting in the patients losing hope.

Key findings included a hierarchy of themes and subthemes as determined from the participants' responses, which I entered into the Nvivo program. Patients between 18 and 23 years old had lived with an obstetric fistula for at least one year. All had been married. Most were now separated or divorced. The medical personnel were all female and older, with median age of 38 years, and median experience of 7 years working with obstetric fistula patients.

Barriers to care described by the patients included financial constraints, men's responsibility for decision-making, the preference for local traditional healers, the disrespectful way they have been treated by healthcare workers, and recent fears because of the Ebola outbreak. Consequences of obstetric fistula included ostracism, bitterness, depression, worsened poverty, fear of gossip including accusations of witchcraft, physical complications of paralysis and foot dragging (because of nerves damaged in childbirth), and, on the other hand, rescue by good Samaritans.

Nurses observed barriers of rural women’s distance from facilities, lack of awareness of obstetric fistula, youth, financial and transportation constraints, embarrassment, belief in traditional healers, and pressure from men. They also observed the consequences of divorce, ostracism, stigmatization including accusations of witchcraft, emotional harm, worsened poverty, physical and mental illness, and difficulty re-entering society. Nurses felt that obstetric fistula was likely to remain a problem, although since they have seen increased awareness and education of birth assistants, they hoped that there would soon be some helpful changes.

Surgeons also recognized the financial constraints, as well as the women's embarrassment when they seek treatment, their stigmatization in their communities, and their preference for traditional healers. They also recognized the mental and emotional problems, ostracism, and worsened poverty faced by many.

The interviews I conducted with fistula nurses and fistula surgeons confirmed the answers provided by patient participants in this study; therefore triangulation of the data in this study ensures that the information gained is valid and pertinent concerning obstetric fistula experiences of patients in Sierra Leone.

Interpretation of the Findings

This study confirms previous findings that obstetric fistula is common in women and girls who receive inadequate medical care during childbirth (UNPF, 2012), and who have prolonged labor (Zheng & Anderson, 2009). In particular, the descriptions from both the women and the medical professionals who provided their healthcare confirmed that obstetric fistula results in devastating physical, emotional, and socio-economic consequences (UNPF, 2013; Wall, 2006).

As I detail below, most previous studies have been conducted in other countries in Africa and Asia, and have focused upon the barriers to women receiving proper medical care. As noted by Roush (2009) and evident in my literature review, there is much less information available on the patients' lived experiences, which may provide policymakers with increased understanding of the severity of the problem of obstetric fistula. Leung and Chung (2009) have documented that policymakers do not see obstetric fistula as an emergency and so do not prioritize funding for treatment. The findings of this study

therefore add to the body of scientific literature regarding obstetric fistula in areas of the developing world by examining the situation of barriers to treatment in Sierra Leone. My findings also add information related to the experiences of fistula as lived by patients with this severe complication.

Experiences of Obstetric Fistula

Financial experiences with obstetric fistula. As I detailed in Chapter 4, financial experiences with obstetric fistula included loss of income associated with the fistula and its treatment, potentially to the point of homelessness and starvation. As a result, women often did not take enough time off to heal from fistula surgery, resulting in increased rates of complications.

Agreements and differences between patients and medical personnel. Medical personnel were well aware of the difficulty of accessing treatment and the consequences that the length of treatment imposed upon women's financial situations. Nurses in particular emphasized the severity of financial considerations, including homelessness and starvation. Doctors were very concerned about women who did not take adequate time to heal before returning to work, and about the relatively high rate of infection.

Confirmation of existing literature. This study's findings confirm Wall's (2006) findings that impoverished countries have a much higher rate of infection in patients with obstetric fistula. They also confirm the findings of the UNPF (2013) that women with obstetric fistula have difficulty finding work and so become even more deeply impoverished. They can be left so weak after surgery that they are unable to resume work or childcare (Storeng et al., 2010). In addition, these experiences are related to Wall's

(2012) framework of remote determinants of obstetric fistula, which have to do with women's status in their communities and the communities' status in the country. The more poverty and the lower the status, the higher the risks of obstetric fistula.

Preview of recommendations. Countries with so few financial resources will probably need to convince intergovernmental and nongovernmental organizations to provide significant donations for these countries to increase their healthcare infrastructure. This is money well spent as it will create jobs in the healthcare industry in addition to returning patients to the workforce after recovery.

Emotional experiences of obstetric fistula. As I detailed in Chapter 4, emotional experiences of obstetric fistula included common feelings of becoming hardened, bitter and hopeless, low self esteem, mental and emotional distress, and even clinical depression.

Agreements and differences between patients and medical personnel. Medical personnel interviewed for this study were aware that their patients experienced significant emotional distress because of their experiences of obstetric fistula and the reactions of their families and communities to women with this condition. They did not appear to be as aware of the aftereffects of bitterness and hardening against their former support systems, as they often encouraged women to reintegrate into their communities. This may have been the best solution because of limited resources for women to proceed on their own. However, it is possible that returning to communities and families where the women were once shunned is difficult or impossible for recovering women.

Confirmation of existing literature. Wall (2006) also detailed the experiences of depression and even suicidal ideation in women with obstetric fistula in third world countries. Storeng et al. (2010) conducted in-depth interviews with women with obstetric fistula and other complications of pregnancy in Burkina Faso and found similar emotions of loss, stress, and trauma.

Preview of recommendations. The emotions experienced by women with obstetric fistula arise (a) from being given inaccurate information about their condition, which can be resolved by educating healthcare workers; (b) from being shunned by their families and communities, which can be significantly lessened with increased resources for women with this condition and education regarding the medical nature of OF; and (c) from fear of receiving poor treatment by healthcare workers, which can also be resolved by better education and perhaps by increased wages for workers so that more caring ones can be selected.

Social experiences of obstetric fistula. As detailed in Chapter 4, social experiences of obstetric fistula included abandonment by husbands, families, and communities, including desertion, shunning, ostracism, lack of a support system through the healing process, stigma, toxic gossip, and accusations of witchcraft. On the positive side, these women usually experienced the intervention of one or more good Samaritans who provided them with practical and emotional support, such as opening their homes and getting them to hospitals.

Agreements and differences between patients and medical personnel. Medical personnel were aware of many of the social problems faced by their patients with

obstetric fistula, including stigmatization and the problems of a patriarchal society. Interestingly, none of the medical personnel indicated any awareness of the intervention of good Samaritans in the lives of their patients.

Confirmation of and differences in existing literature. These experiences support the findings of the UNPF (2013) that women with obstetric fistula are subject to stigmatization, abandonment, and isolation; they are often rejected by their families because of urinary incontinence (UNPF, 2014). Husbands can be punitive rather than supportive, even if they do not divorce their wives (Storeng et al., 2010). Maulet et al. (2013) also noted the social ostracism of women even after repair of obstetric fistula and recommended that the women receive help with follow-up to ensure reintegration economically and socially.

Interestingly, the study of conditions in Zambia by Holme et al. (2007) found many of the same problems as in other African nations, except that usually husbands did not divorce their wives because of obstetric fistula nor because of its complication of incontinence.

Preview of recommendations. Again, social problems may be mostly resolved with education and increased financial resources. Programs to reintegrate women into their communities may also help. No one has investigated establishing new communities of women who have past experiences of fistula for mutual support, but if this becomes feasible then women may prefer it.

Traditional experiences of obstetric fistula. As detailed in Results, traditional experiences of obstetric fistula included trust in traditional healers or local healers who

seemed to have great medical success locally, emotional support from birth assistants during delivery and traditional healers as they tried to deal with obstetric fistula, and general wariness of hospitals and surgeons.

Agreements and differences between patients and medical personnel. Medical personnel interviewed for this study were aware of their patients' preferences for local healers and birth assistants. While they understood the comfort of being attended by women known to their patients, they of course did not agree that local healers could provide better care than hospital staff. However, they were also aware of the interplay with financial considerations that would make it impossible for every woman to be treated at a healthcare facility, so saw the possibilities for improvements in care by training these local healers and birth assistants.

Confirmation of existing literature. PHR (2010) found that the presence of accurate healthcare information impacts the second axis of accessibility of the AAAQ model. The data in this study demonstrates how beliefs that childbirth should be alright at home with assistance, as well as the beliefs that women with obstetric fistula must be witches, and beliefs that medical doctors could not or would not do much for them, made healthcare less accessible for women in Sierra Leone with obstetric fistula.

The third axis of the AAAQ model (PHR, 2010), acceptability, means that healthcare must accept local cultural norms. In Sierra Leone, the women clearly preferred to endure childbirth at home with an assistant. They also have great respect for traditional healers. Women have felt disrespected when they go to the hospital. These problems with

finding professional medical care acceptable support the AAAQ model that such problems limit access.

The experience of women in this study, when they were cared for by local traditional birth assistants who let them labor for days, and/or traditional healers who put them through intensive treatments that did nothing to alleviate their obstetric fistula, supports the acute clinical determinant level of Wall's (2012) framework of determinants of risk of obstetric fistula. Prolonged labor is considered causative for obstetric fistula (Holme et al., 2007).

Preview of recommendations. To respect local cultural norms, and as a cost effective solution, local traditional healers and local birth assistants can be better educated and trained. In this way, women can begin labor and delivery with the traditional assistance that they prefer, but more readily transferred to hospitals for surgical care when traditional healers and assistance recognize an emergency. As money is made available, more local hospitals will continue to be necessary because emergency deliveries cannot withstand long travel distances; another benefit to these hospitals will be employing local medical personnel. Shefrin (2009) has recommended a strategy of providing fistula surgical centers in more rural areas as part of the solution to risk of obstetric fistula in Ethiopia. Women often felt disrespected by hospital personnel, which is less likely to be a problem when a hospital draws staff from the local community, but attitudes of hospital staff will still need to be trained.

Other Findings

A few other findings did not fit into the above clusters. These included physical sequelae of the difficult birthing processes that patient participants had experienced, such as foot dragging and paralysis.

Agreements and differences between patients and medical personnel. Doctors and nurses raised issues of marriage at a very young age, which was never mentioned by patients. Medical personnel also raised issues regarding the lack of education about obstetric fistula and its treatment options. They noted, however, that in the last few years more education was being provided, so they expressed hope that the situation is improving and will continue to improve.

Confirmation of existing literature. This study adds data to the accessibility axis of the AAAQ model, in which PHR (2010) found that the lack of available healthcare information limits access to healthcare. It is hoped that education will improve access.

The fourth axis of the AAAQ model (PHR, 2010) is quality. Other studies have focused on quality issues such as infection control, running water, 24-hour care (Hsia et al., 2012); the quality of medical procedures and treatments (Olsen, Ndeki, & Norheim, 2005; van der Ries & Savage, 2007); and other aspects of quality that this study did not address. Since the women interviewed did not complain about these issues, either the AWC has a high standard relative to what is available in the region or the women did not realize what the standard of care should be. Infections and inability to remain clean were common in the communities, however, as they have been in other studies (Roush, 2009);

so there are quality issues at the local level that negatively impact the lives of women with obstetric fistulas. Also, women in this study did complain about long waits and being treated disrespectfully at the hospitals. These experiences also support issues of quality of care with delays at the hospitals, as addressed by Wall (2012) and by Thorsen et al.'s (2012) study of Malawi, which increase the risks from obstetric fistula. These issues need to be addressed to further lower risks associated with obstetric fistula.

Incidents of foot dragging and paralysis confirm Wall's (2006) findings of long-term crippling injuries associated with obstetric fistula. Women were usually not told of these possible sequelae prior to labor. This was also a problem in Niger (Heller, 2014), where women were also told that incontinence was normal and nothing could be done.

The young age of many of the mothers in this study, which increases the incidence of fistula, adds to similar findings reported in Ethiopia by Muleta et al. (2007) and in Nigeria by Wall et al. (2004); and also supports Wall's (2012) framework of intermediate determinants of risk of obstetric fistula, as does the issue of awareness of healthcare options.

Preview of recommendations. Women should be educated prior to pregnancy of the possible complications and their prevalence in their communities. This may allow some women to make the choice to delay pregnancy or have fewer pregnancies, as they desire not only to stay healthier but to spend less money on childbirth and childcare.

Barriers to Care

Financial constraints. As detailed in the Results section in Chapter 4, financial constraints included inadequate funds to afford the relatively high cost of professional medical treatment, men's responsibility for health decision-making, preference for local traditional healers, the cost and inaccessibility of transportation, monetary loss from time away from work, and loss of financial support from work or family because of the stigma associated with fistula.

Agreements and differences between patients and medical personnel. Medical personnel interviewed for this study, both doctors and nurses at the AWC, were well aware of the financial constraints discouraging their patients from receiving medical care, as well as the role of men in the decision-making process. They spoke at more length of the need for women to take time off after surgery and the women's reluctance because of the need to return to farm work and childcare for those who had other children.

Confirmation of and differences with existing literature. The financial barriers to treatment of obstetric fistula are probably the most studied aspects of obstetric fistula throughout the scientific literature (Ahmed & Holtz, 2007). This is probably because of the widespread understanding that significant financial commitments are needed to combat this problem, yet the countries in the developing world often lack adequate finances.

Researchers s in other countries (Kenya and Uganda) focused upon the practical consequences of lack of finances, including that women delay seeking medical care because of multiple factors affected by finances such as distant healthcare facilities, lack

of transportation, and delays at the hospital before they finally receive care (Echoka et al., 2014; Waiswa et al., 2010). Olsen, Ndeki, and Norheim (2005) found that in Tanzania, a major issue was that hospitals were concentrated in urban areas, making access extremely difficult for rural women. My findings show that even if hospitals were built in greater number so there was greater accessibility, other financial and other factors still would create barriers to care, including the cost of being attended to by medical personnel in those hospitals and often the reluctance of husbands to bear those costs. Similar findings were reported by Okoy et al. (2014), who conducted in-depth interviews with women with obstetric fistula in Nigeria.

The financial barriers detailed in this study confirm many aspects of the AAAQ model reviewed earlier (PHR, 2010). The AAAQ model addresses more closely the role of national policies in making healthcare more widely available. Availability considers the number of facilities, goods, and services (PHR, 2010; Parkhurst & Ssengooba, 2009). As can be seen in the present case, Sierra Leone has low numbers of these. The facilities are too distant. There are few available goods. Services such as birth assistants are available, but well trained assistants are much more rare.

The second axis of the AAAQ model, accessibility (PHR, 2010), examines the affordability of medical care. Many stories were told in the present study of decisions to stay home because procedures at the hospital were not affordable. This was similar to Meyer et al.'s (2007) study in Niger that showed that the very poor have virtually no access to proper medical care because it is unaffordable. Accessibility is also affected by the way in which men make decisions for women, and the men would often decide that

their women could withstand childbirth at home – and yet when the decision proved a poor one, the men would often abandon their wives because of the resulting obstetric fistula. Studies of women in Ethiopia, Nigeria, Ghana, Niger, Zambia, Kenya, Tanzania, and Uganda found approximately 50% of the women in the studies abandoned by their husbands after they developed obstetric fistula (Zheng & Anderson, 2009). Van der Ries and Savage (2007) found affordability of care to be even more important than quality of care, although they focused upon providing the highest quality at the lowest cost. Heller (2014) found that another consequence of such patriarchal societies was that women were not told what to expect after childbirth, nor were they told what surgeries were or could be performed.

This study also provides data to support the theoretical Three Delays model of barriers to medical care (Maulet et al., 2013; Thaddeus & Maine, 1994), the first delay of which is individual decision-making. The respondents in the current study told of individual decision-making that included avoiding medical care in part because of affordability and transportation issues.

The findings of the current study regarding finances and their implications provide data confirming sources of the second delay of the Three Delay model (Thaddeus & Maine, 1994): Delays in identifying and getting to a healthcare facility. These delays appear to be common in poverty-stricken areas that lack adequate resources. Maulet et al.'s (2013) study in Niger demonstrated median delays from the occurrence of obstetric fistula to women arriving for treatment of obstetric fistula to be approximately four years, with weeks more of delays until they could be scheduled for surgery. The median time at

the hospital was seven months. Unfortunately, I did not ask women about the amount of time involved in their delays, and this may be a fruitful discussion for follow-up research as we try to set priorities.

Women in the current study identified problems getting to healthcare facilities; there were no hospitals nearby, roads were inadequate, transportation was seldom available or expensive. Women would not know any healthcare providers at a distant facility, whereas birth assistants were women in their villages who made them feel comfortable. Particularly when they saw many women give birth without complications, they preferred to think that they also could give birth at home without complication. All these contributed to this second delay.

Preview of recommendations. Given the great financial need, countries need to invest in as many hospitals as possible for greater access, but it is unlikely that the number of hospitals will meet the need in the near future. Meanwhile, a more cost effective solution may be better training of local healthcare providers including traditional healers and birth assistants, so that they do a better job of assisting and healing and have better knowledge when a situation is developing into an emergency needing a higher level of care. Both the medical personnel in this study and interviewees in studies in Uganda and Kenya (Echoka et al., 2014; Waiswa et al., 2010) cited failure to recognize a developing emergency as a limitation to women receiving proper treatment to prevent obstetric fistula.

Emotional barriers to treatment. As detailed in results, emotional barriers included embarrassment, shame, dislike of medical personnel, fear of Ebola at the hospital (a realistic fear at the time this study was carried out), and fear of abandonment.

Agreements and differences between patients and medical personnel. Medical personnel interviewed for this study were aware of some of the emotional barriers to treatment experienced by patients. They were aware that they were embarrassed by odors and felt shame in revealing their bodies to strangers. They were aware of their fears of abandonment and ostracism from their homes and communities. However, they were not aware of the previous experiences that many of the women had experienced at other local hospitals, where hospital personnel had embarrassed and shamed them and failed to keep them informed, and that this was the reason for some of their embarrassment in their current situation and reluctance to seek treatment from medical providers.

Confirmation of existing literature. The Three Delays model describes decision-making barriers to obtaining medical care that include individual decision-making (Thaddeus & Maine, 1994). Emotional reactions to the experiences of medical care will drive much of individual decision-making. The respondents in the current study told of being treated poorly by some healthcare workers at hospitals, and not desiring to have further healthcare experiences that left them feeling demeaned. Okoy et al. (2014) reported similar feelings that led to avoidance of future medical services in their study of women with obstetric fistula in Nigeria. In cases where women had unpleasant experiences with the healthcare system in the past, they were, as predicted, less likely to seek professional medical care in the future. Feelings of shame that caused women to

avoid medical care included reticence to expose their bodies to medical doctors and being treated rudely because of smells that they were helpless to prevent. The fear of Ebola that kept some women away from the hospital was also observed by Black (2015) in Sierra Leone and other affected West African nations.

This study also illustrated the third delay of the Three Delay model (Thaddeus & Maine, 1994): Delays in obtaining appropriate care after arrival at the facility. There was a difference in this study with the study of Waiswa et al. (2010) in Uganda. There, a major significant risk for the development of obstetric fistula and other complications, including neonatal deaths, was the delay in medical care after patients arrived at the hospital. This was not as significant a factor in the present study, probably because of more factors in the patients' environment that led to a preference to avoid the hospital for labor and delivery.

Preview of recommendations. There is no excuse for medical healthcare providers to treat women arrogantly and cause them shame and embarrassment over their condition. Also, women should not be treated as if they have no agency; they have the right to knowledge about their condition, surgical treatments, and alternatives. Hospital personnel need significant training to remove the barriers that they are placing inadvertently by their own actions. Increased pay might also help by providing hospitals with more choice of personnel to hire.

Social barriers to treatment. As detailed in results, social barriers to treatment included stigma, accusations of witchcraft, abandonment, and ostracism.

Agreements and differences between patients and medical personnel. Medical personnel interviewed for this study understood the stigmatization of women with obstetric fistula in their local communities. They mentioned not only the difficulties with ostracism, including the emotional and physical consequences, but were even aware that their patients were often accused of witchcraft. Nurses also mentioned the patriarchy that the women live under as a social barrier, as men's decisions put pressure on women to avoid modern expensive healthcare.

Confirmation of and differences in existing literature. These experiences support the findings of the UNPF (2013) that women with obstetric fistula are subject to stigmatization, abandonment and isolation; Wall's (2012) findings that women are stigmatized and isolated; and Browning's (2004) findings that isolation and stigmatization often leads to divorce. Interestingly, Wall's (2012) study found another cause of ostracism that was not mentioned in the current study: In addition to smells and accusations of witchcraft and intolerance of sickness, some believed that obstetric fistula was an indication that the women had acted immorally.

Preview of recommendations. Education may lower the incidence of social ostracism. When women understand that obstetric fistula is a medical condition, there will likely be less fear and rejection of women who suffer from obstetric fistula through no fault of their own.

Traditional barriers to treatment. As detailed in Results, traditional barriers include the easy accessibility to local healers and birth assistants, herbal medicine, local

"cures" for witchcraft, apparent local successes with these, and beliefs that women's bodies should not be exposed to unrelated men.

Agreements and differences between patients and medical personnel. Medical personnel interviewed for this study understand patient preference for local healers and birth assistants, and the issue of embarrassment around medical personnel. However, medical personnel have concerns about the knowledge and ability of local healers and assistants to deal with the array of problems that can arise during childbirth. They recognize that there are not enough hospital facilities, and so did seem open to the provision of better training for local healers and birth assistants so that healers and assistants could more effectively intervene and be more aware of the need for professional medical intervention in complicated cases. In uncomplicated cases, however, healers and assistants would relieve some of the burden on the system at a lower cost.

Confirmation of existing literature. These traditional barriers provide supporting data to the individual decision-making delays of the Three Delays model (Thaddeus & Maine, 1994) of barriers to medical care. The respondents in the current study told of individual decision-making that included preferences for home birth because of trust in traditional healers.

Preview of recommendations. As noted above, better training may allow for women to safely use local healers and birth assistants for uncomplicated pregnancies, while essentially providing triage to determine which women need to proceed to medical facilities.

Limitations of the Findings

Generalizability

A small sample size and the use of a sample of convenience limit the ability of the study findings to be generalized and transferred to a larger population. This is not uncommon with preliminary phenomenological studies. However, a range of women was interviewed in terms of ethnicity, region of origin within Sierra Leone, and economic and other considerations. There is no reason to think that the experience of other women would be dissimilar. Furthermore, this study is not attempting to provide conclusions regarding prevalence, but rather the phenomenological experience of those who suffer from this condition. Other studies have delineated the appalling prevalence of the phenomena, such as those conducted by the World Health Organization (WHO, 2014).

Face-to-Face Interviews and Social Desirability

Another limitation is in the nature of collecting interview data. Respondents have a tendency to want to appear socially appropriate to researchers. This tendency may be somewhat addressed with instruments such as computer-based surveys, where no face-to-face interaction is required. Until more information is available from which to derive such surveys, however, computers are not likely to be helpful in data collection. Every attempt was made to put the interviewees at ease and to provide unconditional acceptance that allowed women to open up to the interviewer.

Translation English-Krio-English

Another limitation is potential problems with translation to and from English. Context and subtext can be lost in translation. The native Krio speaker interviewer had

been trained in health services management in the United States, and was therefore familiar with linguistic and cultural nuances. Every attempt was made to confirm the reliability of the translations to and from English, to ensure that they reflected the actual meaning intended by all parties. Among other confirmatory strategies, researchers reconnected with the women to verify their statements after they were transcribed.

Researcher Bias

A final limitation is the possibility of researcher bias. Analysis of the qualitative interview data required interpretation that may have entailed value judgments on the part of myself, the researcher. Within the need to organize the material, every effort was made to allow the respondents to speak for themselves. Mitigation attempts included having a second researcher check that the analyses were accurate and consistent with the intent of the respondents. Reflexivity and bracketing were also used to help reduce interviewer and interpretation bias. It is therefore believed that everything has been done to ensure this study's trustworthiness.

Recommendations

1. Beyond our scope: Need for further research.

The literature review included several topics that have not been adequately addressed by other studies and were beyond the scope of this study as well. These topics include ways to transform the local culture so that girls are not marrying and getting pregnant so young, as young age is a risk factor for obstetric fistula. Another particular concern is that surgical techniques and postoperative care for obstetric fistula have not been extensively studied. Few clinical studies have been performed (one that has been is

Arrowsmith et al., 2010), and best practices have not been defined. This open doors for further research.

2. Need for national and local strategies to combat early and forced marriage

One of the risk factors for contracting OF is adolescent pregnancy which normally stems from early and forced marriage engendered by harmful traditional practices which perpetrate child marriage that are fueled by ignorance, poverty, and limited exposure. The culture of child marriage exposes girls and young women to violence including marital rape, sexual and domestic violence, and emotional abuse. The risk even increases when there are large gaps in age between a girl and her husband. Girls with low level of education are at higher risk for such harmful traditional practices. Since the harms caused by child marriage are grim, a comprehensive national strategy for combating child marriage is critical with commitment of resources. Such strategy should include legislation that prohibits marriage below the age of 18, establishment of shelters or safe space where girls can seek protection when at risk of child marriage, or when they run away from such arrangement, and awareness raising campaigns on the phenomenon of early marriage targeting the main actors in the health sector and the community. Marriage should only be allowed with the consent of the adolescent at an acceptable age.

3. Increased access to skilled birth attendants.

Effective monitoring of labor is crucial to the prevention of OF. This include strategies to ensure that women have access to skilled birth attendance and program designed to ensure that prolonged labor is identified and managed in a timely manner. This strategy should also include improved access to emergency obstetric care that

guarantees swift and safe Caesarean sections for women in obstructed labor. Access to competent medical care for women during and after obstructed labor will lead to early detection and treatment of OF.

4. Political commitment toward maternal health improvement

As fistula continue to be a neglected disease affecting a vulnerable, excluded and stigmatized population in Sierra Leone, political commitment toward making maternal health a priority with sustained resource allocation is crucial. Such effort should include increased access to family planning services and increased educational opportunities for girls and women. Strong focus on adolescents' rights to health information and services that include contraceptives, addressing factors that contribute to unplanned pregnancy, and training health workers on engaging adolescents are crucial to prevent OF in Sierra Leone.

5. Improved access to transportation and health facilities as the most efficient methods of intervention

Although the AAAQ and Three Delays models clarify areas of particular concern and possible intervention, the best ways to intervene that would fix identified problems have not been determined. Transportation costs for the most part were considered to be a major barrier to access care for many women with OF in Sierra Leone. One interesting recent development has been the use of motorbike ambulances in rural Sierra Leone (Bhopal et al., 2012). This may help increase accessibility by improving transportation to the hospital. However, although reported five years ago, they were not in regular common use at the time of the current study. Furthermore, other than perhaps with the

use of high-speed ambulance services, the lack of facilities really cannot be entirely addressed by increased transportation, since facilities need to be as close to patients as possible for emergencies that require as immediate a response as possible.

6. Outcome studies of intervention after implementation

A recommendation could be made for larger studies of the barriers to care and consequences of complications with the bid to confirm my findings. The stories of women in their own words have an emotional impact that statistics will never have. It is hoped that policy-makers will be made more aware of the extent and severity of this problem and respond accordingly. As interventions are implemented, there is a role for further research to determine which interventions are most effective at least cost in the prevention and treatment of obstetric fistula and the other complications of pregnancy.

Implications

The childbirth complication of obstetric fistula ruins the lives of women who even without medical issues face poverty and powerlessness, adding to their struggles physical ill health, emotional and social harm, and loss of dignity and self-esteem (Mselle et al., 2011). The prevalence of obstetric fistula reflects the medical, social, and political failure of nations to provide proper maternal healthcare and treatment for its most vulnerable peoples.

This study is the first to explore the experiences and perceptions of women and girls in Sierra Leone who have been suffering with obstetric fistula, and their healthcare workers, who reflect a good understanding of their patients' suffering. As such, this study adds substantially to the pool of knowledge on this issue, which has received neither

public awareness nor intervention. The study sheds light on predisposing factors and barriers to seeking care. Without such information, advocacy is hampered. Hopefully, these results will create much-needed awareness about the condition. This in turn will ideally stimulate policy-makers to rise to the challenge of discouraging child marriages and genital mutilations, while expanding emergency obstetrical services and the education of birth assistants in rural communities, where the complications of pregnancy are most prevalent.

Conclusion

Sierra Leone has the worst maternal morbidity and mortality rates in the world, but there is no reason for rates to remain so high. Several factors that feed into barriers for care, such as high costs, fear of hospital treatment, severely inadequate OF treatment, physical sequelae including paralysis and foot dragging, and a preference for traditional birth assistants offer several points at which intervention can be effective. Effective advocacy requires adequate information to present to policy-makers, and the present study of patient experiences, including stigmatization, abandonment by family, embitterment, depression, and job loss, in conjunction with previous studies of prevalence combine to present an effective portrait of the severity of this issue. All interventions require adequate funding. However, funding could ensure education and awareness campaigns to help women take charge of their healthcare decisions and identify the closest clinics and hospitals that can help them during pregnancy and delivery; funding could improve roads and transportation options and therefore improve accessibility; funding could help cover hospital costs for poor women; funding could

provide education for birth assistants, who would then be better able to care for the women they assist and better able to recognize the need for more advanced medical intervention; and funding could provide training and adequate funding of healthcare workers to foster more sensitivity for the needs of women, rural residents, and the poor. Hopefully the recognition of the ways in which lives are ruined by the lack of relatively inexpensive healthcare options will spur policy-makers to dedicate funds to the resolution of the problems of obstetric fistula and other complications of pregnancy.

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Appendix A: Socio-Demographic Information of Patients

1. Name or Number----------
2. Age _____
3. Town and region of residence _____
4. Marital status_____
5. Primary school education_____
6. Number of living childbirth_____
7. Did your baby die when fistula was developed_____
8. Employment_____
9. Religious denomination_____
10. Household income_____
11. Number of years living with fistula_____.
12. Are you currently being treated for your fistula?_____

Thank you for participating in this research. If you have any questions or concerns about this interview, please let me know and I will do my best to help. All information will be used in order to help understand the problem of obstetric fistula better.

Appendix B: Socio-Demographic Information of Health Care Workers

1. Name or Number_____
2. Age_____
3. Gender_____
4. Job title_____
5. Department_____
6. How long have you worked with obstetric fistula patients?_____

Thank you for participating in this research. If you have any questions or concerns about the way that your answers will be used, or any other problems, please contact me as soon as possible and we will do our best to help.

Appendix C: Interview Questions for Patients and Health Workers

INTERVIEW QUESTION FOR PATIENTS

Questions on experience and perception will include**:**

1. Please tell me how the fistula developed.
2. How did you find out that it was fistula?
3. What did you do about it?
4. Please describe your experience living with fistula.
5. Do you think healthcare workers are doing enough to help prevent the problems of obstetric fistula in your area? If not, do you have any suggestions for them?

Questions relating to participants awareness include:

6. Do you think that obstetric fistula is getting more common in your area? (if yes) why?
7. What would you say are the causes of fistula?
8. Are you aware of things that can be done to prevent the condition?
9. Would you pass on this knowledge to other women to help them avoid having the same issues as you have?
10. What are the consequences of obstetric fistula for women in Sierra Leone?

Specific question relating to the consequences of fistula will include:

11. What are the consequences of obstetric fistula for women in Sierra Leone?

Specific questions relating to the participants perceptions of barriers to care will include:

12. Tell me about your experience in seeking care for your fistula.
13. Was there anything that may have prevented you from seeking care? Did that change when you began leaking?
14. Is there anything that would have made you more likely to seek medical treatment before you experienced your fistula, for example receiving more information about the risk of fistula, hearing stories from other women that have given birth?

Questions about social support will include:

15. Tell me about people who are most important in your life
16. How has your relationship change since you started leaking?

Questions about coping will include:

17. Tell me how you deal with your fistula.
18. After experiencing obstetric fistula yourself, is there anything you would advise friends and family about childbirth and ensuring that the correct medical care is received?
19. Is there anything else you would like to tell me that has not been mentioned?

Thank you for participating in this research. If you have any questions or concerns about the way that your answers will be used, or any other problems, please let me know as soon as possible and I will do our best to help. All information will be used in order to help understand the problem of obstetric fistula better.

INTERVIEW QUESTIONS FOR HEALTHCARE WORKERS

1. How can you describe the present state of obstetric fistula in Sierra Leone in terms of awareness, prevalence, concern among health planners, and non-governmental organizations(NGOs)?
2. What are the challenges encountered by fistula survivor?
3. Please describe any other health facilities like yours that are specialized in treatment and rehabilitation of fistula patients.
4. Please describe any financial reasons why women may not seek appropriate maternity or prenatal care.
5. What are the consequences of obstetric fistula for these women, aside from the direct impact on their physical health, such as embarrassment, mental health issues, social issues, or other non-medical issues?
6. What kinds of community and social needs are currently available for assisting women to know about services and helping them to re-integrate into society after successful repair?
7. Please describe any social reasons why women do not seek appropriate maternal care.
8. Please tell me any other reasons that contribute to the problem of maternal care in Sierra Leone.
9. What do you think are the major consequences of obstetric fistula? How do you think it affects these women?

10. Some people think that obstetric fistula will continue to be a problem in Sierra Leone. What would you say about that?
11. Do you think that the consequences of obstetric fistula are well enough recognized by health policy-makers to improve women's access to care? Are they well enough to help highlight the need for maternal care in Sierra Leone?
12. Is there anything else you think is important to know about obstetric fistula that might help people to understand the issue further?

Thank you for participating in this research. If you have any questions or concerns about the way that your answers will be used, or any other problems, please contact me as soon as possible and we will do our best to help.

Appendix D: Flyer – English Version

STUDY ADVERTISEMENT

Patients with obstetric fistula and their Medical Personnel Needed!!!

I am looking for Patients with obstetric fistula and their Medical Personnel to participate in a 40 minutes to 1 hour taped interview concerning their experiences of living with the disease and caring for the patients.

Confidentiality is my first priority.

I am a PhD student in Public Health at Walden University in Minneapolis, Minnesota, USA conducting graduate research on people living with obstetric fistula and their medical personnel and related experiences living with the disease and caring for the patients.

I want to hear your story!

Who can Participate?

Patients of obstetric fistula who have lived with the disease for at least a year and are currently receiving treatment at the Aberdeen Women Center and their medical personnel at the Aberdeen Women Center who have worked with fistula patients for at least a year who can participate in a 40 minutes to 1 hour audio recorded private interview.

Every patient who participates will receive a snack and a deodorant and medical personnel a snack and a pocket sized diary for participating in the study.

Private interview location is secured.

For more information or to become a participant, please call Sheku Samba at +17632449293

Deadline to enroll is October 10, 2016.

Make your voice heard!

Research is conducted through Walden University-Minneapolis Walden University IRB Approval # 09-16-16- 0276483 and it expires September 15, 2017

Appendix E: Flyer-Krio Version

A P P E N D I X G FLAYA INHLISH

OBSTETRIC FISTULA: Di Gekspirens we sik pipul en di welbodi wokman den na Salom nid.

STODI ADVATISMENT

Di sik pipul den wit Fistula en den welbodi wokman want!!

A de luk fo pipil dem we don get Fistula en dem welbodi wokman dem fo tek pat pan 40 minit tete wan awa tep intavyu we wi to tok bot den ekspirens from di tayn we den don get di sik.

A GO KIP OLTIN SIKRIT

Mi na PhD student pan poblik Helt na Walden Univasiti insay Minneapolis, Minnesota, U. S. A. A de komdokt graduate rishach bot pipul dem we don get Fistula en den welbodi wokman den. Sem we so, den Ekspirens as aw dem de liv wit dis sik yaso, a want no aw den de kia fo den.

Udat fo tek pat pan dis intavyu?

Enibodi we den get dis sik yaso fo wan ia en den de tek tritment na Ibadin uman senta we dem wok wit den sik pipul yaso insay wan ia go tek pat. Sem we so, den fo tek 40 minits tete wan awa we a go rekod den voys sikrit. Eni sik pesin we tek pat pan dis wok yaso go get smak en fayn swit smol dyudorant. Also, Eni welbodi wokman we tek pat pan dis wok go get smak en wan fayn poket sayz diari.

Usay yu go-aks yu di ples sef.

If yu want no mo bot dis wok o if yu wan tek pat, duya na fo kol Skoku Samba pan dis nomba yaso: 011-232-763-244-9293

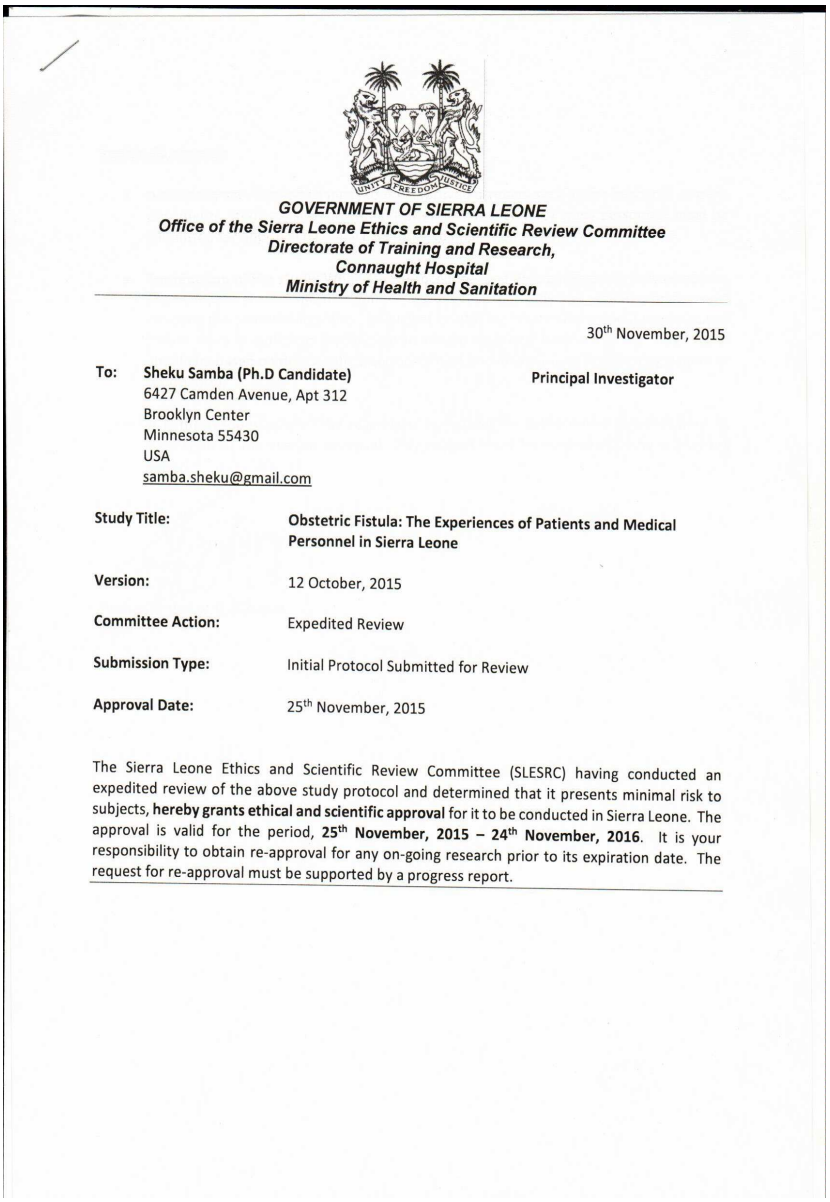
Di tayn we dis applikeshon de klos na novemba 1, 2015.

Duya, mek me pipul dem no bot yu.

Dis risgach na wan Univasiti we de Minneapolis Walden Univasiti du am.

DEN DON CHEK OLTIN!!

Appendix F: Sierra Leone Ethics and Scientific Review Committee Approval Letter



GOVERNMENT OF SIERRA LEONE
Office of the Sierra Leone Ethics and Scientific Review Committee
Directorate of Training and Research,
Connaught Hospital
Ministry of Health and Sanitation

30th November, 2015

To: **Sheku Samba (Ph.D Candidate)** **Principal Investigator**
6427 Camden Avenue, Apt 312
Brooklyn Center
Minnesota 55430
USA
samba.sheku@gmail.com

Study Title: **Obstetric Fistula: The Experiences of Patients and Medical Personnel in Sierra Leone**

Version: 12 October, 2015

Committee Action: Expedited Review

Submission Type: Initial Protocol Submitted for Review

Approval Date: 25th November, 2015

The Sierra Leone Ethics and Scientific Review Committee (SLESRC) having conducted an expedited review of the above study protocol and determined that it presents minimal risk to subjects, **hereby grants ethical and scientific approval** for it to be conducted in Sierra Leone. The approval is valid for the period, **25th November, 2015 – 24th November, 2016**. It is your responsibility to obtain re-approval for any on-going research prior to its expiration date. The request for re-approval must be supported by a progress report.

Review Comments:

- **Amendments:** Intended changes to the approved protocol such as the informed consent documents, study design, recruitment of participants and key study personnel, must be submitted for approval by the SLESRC prior to implementation.

- **Termination of the study:** When study procedures and data analyses are fully complete, please inform the SLESRC that you are terminating the study and submit a brief report covering the protocol activities. Individual identifying information should be destroyed unless there is sufficient justification to retain, approved by the SLESRC. All findings should be based on de-identified aggregate data and all published results in aggregate or group form.

- It is the responsibility of the researcher to request for extension of approval prior to expiration of the current approval. This request must be accompanied by a progress report.

Professor Hector G. Morgan
Chair

Appendix G: Letter of Cooperation from Aberdeen Women's Center

Mr. Sheku Samba

Walden University

Academic Offices: 100 Washington Avenue

South, Suite 900, Minneapolis

MN 55401

4th November 2015

Dear Mr. Sheku Samba,

Based on my review of your research proposal, I give permission for you to conduct the study entitled "**Obstetric Fistula: The Experiences of Patients and Medical Personnel in Sierra Leone"** within the Aberdeen Women's Centre. As part of this study, I authorize you to Visit the center, freely meet with obstetric fistula patients and their healthcare workers, display flyers, recruit participants, conduct interviews, and present

the research outcome. Individuals' participation will be voluntary and at their own discretion.

We understand that our organization's responsibilities include: help in displaying flyers, granting access into the center, allowing access to obstetric fistula patients and their healthcare workers, providing a room for the conduction of individual interview, provision of a counselor, and a space for presentation of research result. We reserve the right to withdraw from the study at any time if our circumstances change. The student will be responsible for complying with our site's research policies.

I confirm that I am authorized to approve research in this setting and that this plan complies with the organization's policies.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the student's supervising faculty/staff without permission from the Walden University IRB.

Yours Sincerely,

Augustine F. Kutubu-Kosia

Senior Program Manager

Aberdeen Women's Centre

Formerly Mercy Ships Sierra Leone

Cape Road at: Aberdeen Roundabout

Freetown

Sierra Leone

025-260817

augustino.kosia@aberdeenwomenscentre.org

CC: Dr. Michael Schwab

Core Faculty, College of Health Sciences

Walden University

CC: File