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Sources of Informal Support for Women Experiencing Obstetrical Fistula: A Focused Ethnographic Study

by

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Dedication

To the women and men who joined with me in conversations. These are your stories and this is dedicated to you.

Abstract

Obstetric fistula is a devastating complication of childbirth and a neglected global health issue. Ghana, a low-income country in sub-Saharan Africa is faced with high maternal mortality and morbidity rates including an estimated 500 to 1000 new cases of obstetric fistula every year. In this qualitative study the perception of support experienced by women who have or have had an obstetric fistula, and those close to these women is explored. In depth interviews were conducted with 14 participants. Findings revealed perceptions of support reported by self, spousal, familial, community and formal sources that are particularly focused on information and economic support. Recommendations include strategies to improve access to treatment for women living with obstetric fistula, to direct resources and create a dedicated specialist fistula centre in Tamale, and providing education to front line health workers on strategies to prevent obstetric fistula and promote safe motherhood practices.

Keywords: obstetric fistula, vesicovaginal fistula, rectovaginal fistula, rectovaginal fistula Ghana, maternal health, maternal morbidity, gender, social determinants of health, inequity

Preface

This thesis is an original work by Ginger Sullivan. The research project, of which this thesis is part, received ethics approval from the University of Alberta Research Ethics Board, Project Name “Sources of Informal Support for women experiencing Obstetrical Fistula: A Focused Ethnographic Study”, No. Pro00042252, 13, September, 2013. This research project also received research ethics approval from the Navrongo Health Research Centre Institutional Review Board, Approval ID: NHRCIRB167, 21, October, 2013.

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Chapter 1

Introduction

Every minute, somewhere in the world a mother dies from a pregnancy-related complication (World Health Organization [WHO], 2010). For every woman who dies during pregnancy or childbirth, 23 will suffer from a related complication; one of the most severe is obstetric fistula (OF) (WHO, 2010). Obstetric fistula (OF) is defined as an abnormal opening between the vagina and rectum or the vagina and bladder, and if left untreated, results in urinary and/or fecal incontinence (WHO, 2007). OF is most commonly a result of obstructed labour. In higher income countries, the incidence of OF due to obstructed labour is rare as a result of universal and funded access to skilled attendants at birth. Women in low-income countries often do not have access to either medical or financial resources needed to have their OF repaired. As a result, women living with unrepaired OF experience both physical and social repercussions (Roush, 2009). Many of the women with OF are abandoned by their partners, likely due to their shame of and disgust with having a wife who uncontrollably leaks bodily waste. Often times these women are defiled by their communities and left to fend for themselves, facing extreme difficulties in securing even their basic needs (Mwini-Nyaledzigbor, Agana & Pilkington, 2013; Roush, 2009).

1.1 Significance of the Study

Maternal morbidity and mortality are deemed the greatest global health disparities between high and low-income countries (United Nations Children's Fund, 2006). Despite Safe Motherhood Initiatives implemented in Ghana, beginning in 1987, rates of maternal mortality and morbidity remain high, with an estimated 500 to a 1000 new cases of OF occurring in the country each year; the prevalence is especially high in the Northern Region. This estimate is significantly higher than United Nations Financial Disclosure Programme's 2003 estimate of 113 untreated cases in the country (United Nations Population Fund [UNFPA], 2004). Safe Motherhood Initiatives are often targeted solely at women because in sub-Saharan Africa, childbearing is typically viewed as primarily a woman's responsibility (Mbizvo & Bassett, 1996). The failure to include men in such initiatives has limited the success of these maternal health programs (Mbizvo & Bassett). Little evidence was found with respect to mens' perceptions of their roles in preventing and supporting women with OF. Findings from this study will build on the work of Ghanaian colleagues and be shared with them so that recommendations for more effective and culturally safe maternal health interventions, that include perspectives of both genders, are realistic and appropriate.

Chapter 2

Literature Review

2.1 Review of the Literature

With the assistance of a research librarian, search strategies were developed to maximize the retrieval of past evidence. The search strategies used for the literature review included searching the websites of respected global organizations, including the World Health Organization, UNICEF, Engender Health, Fistula Network, and five academic databases: CINAHL, Global Health, MEDLINE, Google Scholar, and PubMed. The keywords searched separately, and in various combinations, included: maternal health, maternal morbidity, sub-Saharan Africa, vesicovaginal fistula, rectovaginal fistula, social implications, obstructed labour (labor), abandonment, divorce, husbands, and families. A flow chart of the selection process and inclusion/exclusion criteria is presented in Appendix A. Significant themes found within the existing published research regarding the social implications of OF will be presented; these include societal role, marital status, stigma associated with the condition, segregation of affected women from the community or family unit, and barriers to accessing healthcare (Mwini-Nyaledzigbor, Agana & Pilkington, 2013; Roush, 2009). A detailed summary is presented in Appendix B and a quality appraisal of the included studies can be found in Appendix C.

2.1.1 Campaigns to end fistula. OF is often referred to as a hidden condition, as it typically affects the more vulnerable members of society – young, poor, and, in most cases, illiterate girls and women living in low-income countries (Bangser et al., 2011). When girls are born in impoverished rural communities where malnutrition is rampant and child marriage is the norm, the risk of developing an OF increases significantly (Bangser et al., 2011; Pope, Bangser, & Requejo, 2011). Once women are affected by OF, the leakage of urine and feces commonly results in their quickly becoming social outcasts, remaining 'hidden' from society's view (Bangser et al., 2011, Pope et al., 2010). Thus, the true extent of the issue is largely unknown. The lack of information and reliable data regarding OF poses grave challenges when planning programs and fistula prevention and treatment campaigns.

OF emerged as a major global health concern early in the millennium, largely as a result of increased public health awareness and the creation of Millennium Development Goal 5 (MGD5) dedicated to improving maternal health (United National Development Programme, 2010). As a result, organizations such as the World Health Organization (WHO), the International Council of Midwives (ICM), and the United Nations Population Fund (UNFPA), together with several other non-governmental organizations, began to sponsor initiatives targeted at combating OF in low-income regions (UNFPA, 2004). For example, in 2003 the UNFPA launched a global campaign to end OF. The campaign was delivered in more than thirty countries in Asia, and the Arab world, and sub-Saharan Africa. The campaign was to be implemented through partnerships with local governments, grassroots organizations, foundations such as the Bill and Melinda Gates Foundation, and corporations (UNFPA, 2004). The aim of the project was to eliminate OF from the low resource areas of the world, making it as rare an occurrence in sub-Saharan Africa as it is in North America (UNFPA, 2004).

As part of the UNFPA campaign, and to address the heavy burden of OF in Ghana, a project was launched from 2005 to 2007 termed, “Strengthen Obstetric Fistula Prevention Activities and Access to Treatment in Ghana” (UNFPA, 2006). Despite this concerted effort, little progress has been in made in terms of preventing, treating and improving the lives of Ghanaian women affected by OF (Futa, 2008). In a recent study conducted by Salamatu Futa, it was reported that although the UNFPA project collected data on the prevalence of OF in the Northern districts of Ghana, a significant number of cases were not identified. For example, healthcare providers in the district of Savelugu-Naton reported having zero cases of OF in the region; however, in Futa’s study conducted only a year later, she found that there were indeed several cases of OF in the Savelugu-Naton district (Futa, 2008). Futa highlighted her impressions that due to the stigma associated with the condition; women and families were often not willing to disclose such information. She further suggested that even with comprehensive OF needs assessment programs, accurate and reliable reporting was not always achieved (Futa, 2008).

Investigators in other parts of West Africa suggest that there are further issues that complicate the success of fistula campaigns. For example, an OF campaign was evaluated in 2009 in Niger (Cam et al., 2009). The campaign was a short-term project focused on providing surgery for women living with untreated OF. Project members consisted of a group of foreign doctors who performed surgery to repair OF at a regional hospital in the Maradi region of the country (Cam et al., 2009). Findings revealed that significant issues arose in terms of the campaign's implementation. A total of 62 women arrived at the hospital and were examined by the team. Several of the women who arrived at the hospital, approximately 9.8%, were extremely malnourished, had active infections, and were severely anemic, so were not always eligible for surgery. Another difficulty faced by project members was the inability for patient follow-up as visiting doctors typically left the area quite soon after the surgeries were completed (Cam et al., 2009). Local providers and health facilities were simply unequipped and unable to provide follow-up or to deal with complications following surgery, should they arise. The investigators concluded that efforts to reduce the heavy burden of OF would require the opening of specialized fistula centres with well trained staff to be located in the countries where the condition is prevalent and that current campaigns, functioning as short-term projects, are not sustainable: "It seems to be impossible to combat OF with short-term programs and short-term volunteers" (Cam et al., 2009, p. X).

2.1.2 Role as a wife and mother. In sub-Saharan Africa, a woman's value in society and her own sense of worth is directly related to her ability to bear children and satisfy her husband (Yeakley, Chipeta, Tauloe, Tsui, & 2009). The effect that OF has on a woman's societal standing, particularly as a wife, partner and mother, is a significant theme in the literature (Roush, 2009). The majority of research evidence supports the popular belief that most women who develop OF are divorced as a consequence of having an OF, and that the divorce is initiated by their husbands (Roush, 2009). In a recent integrative review, divorce is reported to be a common social consequence for most women who develop OF. The review included seven studies: two using quantitative, four using qualitative, and one using a mixed methods design.

Descriptive data in all seven studies provided evidence that marital status is typically lost for women who develop OF (Roush, 2009).

In rural Ghana, the lives of women living with OF are filled with challenges. In the majority of circumstances when a women develops an OF, the baby does not survive (WHO, 2006). A 2007, meta-analysis of eight studies conducted in several sub-Saharan African countries highlighted that an average of 85% of women who experienced OF also experienced fetal loss (Ahmed & Holtz, 2007). Not only are these women left to deal with the grief of losing a child, but they also experience a tremendous amount of shame and stigma. A woman with an OF is often abandoned by her partner and shunned by her community because of her inability to bear more children and her foul smell (Mwini-Nyaledzigbor et al., 2013; Roush, 2009). Already in dire socioeconomic situations, the constant smell of leaking urine and feces results in women spending the very few resources they have on products such as soap and perfume in an attempt to cover up the odor (Mwini-Nyaledzigbor et al., 2013).

In an exploratory research study, focused interviews were conducted with women who experienced OF and ranging in age from 20 to 60 years (mode=45) was conducted in the Upper East Region, specifically the Bawku District of Ghana. The purpose was to explore and describe the experiences of ten women currently living with OF (Mwini-Nyaledzigbor et al., 2013). For women living in the Bawku District, marriages are often arranged by families and take place for wives at a very young age, ranging from 9 to 15 years old. Such early unions result in early pregnancy so that girls are labouring and giving birth when their pelvis has not fully developed; because of this labour is more likely to become obstructed and consequently an OF develops in the obstructed birth passage (Mwini-Nyaledzigbor et al., 2013). The majority of women in this study had lived with their OF for a significant period of time, ranging from four to ten years. All of the women (n=10) experienced the death of their baby during the labour that resulted in the development of an OF. Findings revealed that for these women OF frequently led to divorce and partner abandonment, consequently sinking them further into diminished physical, psychological and socioeconomic circumstances (Mwini-Nyaledzigbor et al., 2013). At the time of the study seven of the ten women remained married; however, all of their husbands had taken other wives. All except one of the participants described experiences of feeling deserted and betrayed when their partners turned to other wives for childbearing, sex and companionship. One participant told of her experience of partner abandonment: " Ever since I developed the condition, we have not been together as husband and wife. He has other wives, so I have been left out here to care for the old lady [mother in-law]. He still remits me once in a while and I am living in his family house. I consider myself as still married but a divorcee in disguise" (Mwini-Nyaledzigbor et al., 2013, p. 451). These findings are congruent with those of previous studies conducted in various parts of East Africa, where partner abandonment not only inflicts emotional and psychological suffering, it strips affected women of economic support, thus significantly diminishing the possibility of them ever receiving care and treatment for their OF.

For women with OF living in East Africa, the story is reported to be much the same. In a recent exploratory study conducted in rural Tanzania, the quality of life for women living with OF was compared with those living without the condition (Pope et al., 2011). Quality of life measures included items such as family and partner support. To compare quality of life, a questionnaire (PQoL Tool*)* was administered to two groups of women (n=71): those affected by OF and those not affected. Women who had been affected by OF had a significantly lower quality of life than women who were not affected (P=0.001). Furthermore, 56% of women with OF were divorced, while only 4.3% of women who did not have an OF were divorced. Of the women who were waiting to have OF repair, only 16% were divorced. This finding was similar to prior research done in Ethiopia, where the average time women lived with the fistula increased, the more likely they were to be divorced (Kelly, 1995; Muleta, Hamlin, Fantahun, Kennedy, & Tafesse, 2008). In a similar mixed method study conducted in Tanzania, it was reported that there was a significant association between living alone (abandonment) and the duration of time women lived with the fistula (P=0.0111) (Mselle, Moland, Evjen-Olsen, Myungi, & Kohi, 2011). Perhaps the longer a woman lives with OF, the more apparent the detrimental effects become; after a prolonged period of suffering, the male partner may realize that his wife is not likely to ever be able to work, have children or satisfy him sexually. All of these factors create strain on the relationship and may influence his decision to divorce her.

Although the majority of evidence supports the claim that most women who develop OF are abandoned by their partners, there is some evidence that this is not always the case. Two recent studies, one in East Africa, and the other in sub-Saharan Africa, suggest that for women with OF, divorce is not inescapable. In rural Ethiopia a study was conducted to assess the urinary and reproductive health and the quality of life of women following surgical repair of OF (Neilson et al., 2009). Follow-up consisted of structured, community-based interviews that took place 14 to 28 months after the repair. Participants were asked to evaluate three time periods during the interview: before developing an OF, during the time living with an OF, and the current time after surgery (Neilson et al., 2009). Results revealed that only 5% of women were divorced after developing an OF (Neilson et al., 2009). This finding is different from the previous descriptive data on the prevalence of divorce. For example, in comparison, in a study conducted in seven administrative regions of rural Ethiopia, it was found that 69.2% of women were divorced after developing an OF (Muleta, Rasmussen, & Kiserud, 2010). It is possible that the discrepancies in Neilson's finding may be attributed to the fact that the incidence of divorce increases as the number of years living with an OF increases. The average number of years the women lived with the fistula in Neilson's sample was three, relatively lower than that reported in most other studies (Bangser et al., 2011;Pope et al., 2011; Roush, 2009).

In a second recent study conducted in Zimbabwe, investigators found that all of the participants, women who had suffered from OF (n=4), were married. The purpose of this exploratory study was to identify and describe, using in-depth interviews, the experiences of four women currently living with OF (Mutambara et al., Maunganidize, & Muchichwa, 2013). Interestingly, all four of the women who had experienced OF remained married even after they had developed the condition. However, findings revealed that although these women were married, they felt that they failed to fulfill their marital role as a wife, and tended to view themselves as worthless, incomplete and "not worthy" (Mutambara et al., 2013, p. 237). Women reported having "failed sex lives," and were no longer able to provide sex or experience intimacy with their husbands due to an inability to control their bodily functions and smell (Mutambara, et al., 2013, p. 237). Many women expressed feelings of living in fear related to their concern that their husbands would eventually remarry. Women worried that because they were no longer able to fulfill their duties as a wife, (i.e. engage in intercourse and bear children) their husbands would start to look for other 'clean' women who were able to engage in intercourse, bear children and who did not leak urine (Mutambara et al., 2013, p. 234-237).

Although all four participants in Mutambara's study remained married, typically they did not feel like their husbands treated them like wives. As in other findings (Mwini-Nyaledzigbor et al., 2013), women suffering from OF were often not allowed to cook, lived in a separate house or room, and did not continue any sort of sexual relationship with their husbands. Nonetheless, others, including Neilson (2009), Mselle et al. (2011) and Maunganidize & Muchichwa (2013), highlight an important point: contrary to the popular belief, divorce of women with OF is neither universal nor inevitable.

Accounts of positive supportive relationships between husbands or partners and the women living with OF were reported in all studies included in this review (Bangser et al., 2011; Mselle et al., 2011; Muleta, et al., 2008; Mwini-Nyaledzigbor et al., 2013; Neilson et al., 2009; Pope et al., 2011; Roush, 2009; Yeakley et al., 2009). In a national mixed method study in Ethiopia, it was found that some women who remained married after acquiring an OF reported that their husbands were both economically and emotionally supportive (Muleta et al., 2008). Men who chose to stay with their wives often provided economic support to ensure the woman's basic needs were met. Supportive husbands would continue to live with their wives in the same house and provide food. In some cases it was reported that men who chose to stay with their wives also provided the funds for the women to receive OF treatment (Mselle et al., 2011; Muleta et al., 2008; Neilson et al., 2009; Pope et al., 2011; Roush, 2009; Yeakley et al., 2009). Not only did women report their partners as being supportive after developing the fistula, they also explained that decisions regarding labour and obstetric care were largely made in conjunction with their husbands (Muleta et al., 2008; Mwini-Nyaledzigbor et al., 2013; Pope et al., 2011). Similarly, the analysis of a social mapping exercise conducted with Tanzanian women who had accessed surgical repair treatment revealed that women identified husbands as one of the key individuals who helped them access obstetrical care and treatment (Pope et al., 2011). Receiving appropriate maternity care significantly decreases the risk of obstructed labour, thus decreasing the risk of OF (WHO, 2007). These findings reveal that partners can play a significant role in supporting their wives/sexual partners by encouraging prenatal care and education to prevent the OF from ever occurring.

Since 2003, with increased OF awareness initiatives, effort has focused on changing attitudes to decrease stigmatization of those with OF, and increasing the access to OF treatment and care (Bangser et al., 2011; Engender Health, 2004). However, many of these campaigns have not included men as key partners, and as result have limited the success of maternal health and OF prevention and treatment campaigns. This highlights a missed opportunity to gain a greater understanding of the availability and type of support women experience when making decisions regarding their reproductive health. No qualitative research study that exclusively examined the husbands'/partners' perceptions of their role in the prevention and management of OF was identified. This study is aimed at addressing this gap.

2.2 Research Question

The purpose of this research study is to answer the following research question: How do partners/spouses or others close to women (mothers, mothers-in-law, close friends, siblings, children) as well as the women themselves in the rural Northern Region of Ghana who have experienced OF describe the support that they give affected women? By exploration of this question the researcher will be able to gain insight about and describe the support provided to women living with OF or who have had an OF in the past.

Chapter 3

Methodology

3.1 Research Design

The qualitative research design best suited to answer the research question is focused ethnography. Ethnography is rooted in anthropology and it is used to understand and describe a particular culture or way of life. Ethnographers use the principle methods of participant observation, formal interviews, and examination of available documents to gain an emic or insider perspective of a particular culture (Muecke, 1994). *The particular culture of interest for this study is the culture of those who are in contact with women who experience(d) OF in the context of Northern Ghana*. To understand how the phenomenon of OF impacts those close to affected women, (especially partners or spouses but also children, mothers, mothers-in-law) the researcher must have an understanding of the context in which this trend occurs. The particular context for this study is women in the Northern Region of Ghana who attend or are known to staff at the Tamale Fistula Centre.

Northern Ghana is home to people of several different and diverse ethnic groups, all speaking different languages. Islam, Christianity, and traditional African folklore are the dominant religions in the region (Mwini-Nyaledzigbor et al., 2013). Despite linguistic and spiritual differences, people from Northern Ghana tend to have cultural similarities that place great value on music, dance, marriage, lineage, family, ceremonies and traditional foods (National Commission on Culture, 2013). The culture surrounding birth in Northern Ghana is such that childbirth is viewed as a natural process. The majority of women prefer to give birth at home with the support of a traditional birth attendant (EngenderHealth, 2004).

One of the aims of ethnography is to "make explicit what is implicit in a culture" (Streubert & Carpenter, 2011, p. 175). Traditionally, ethnography was utilized to explore cultural groups and societies in their natural setting; however, nurses have also widely recognized the significance of ethnography as a method to investigate nursing phenomenon (Streubert & Carpenter, 2011). Ethnography is a research method and consistent with the qualitative methodology paradigm, ethnography does not provide *the* truth; instead it discovers *a* unique and specific view of the truth as it is shaped by culture (Streubert & Carpenter). The process between the researcher and the participants is interactive and ever evolving where the aim of the research is not to discover an ultimate truth but rather describe and consider the meaning assigned to experiences by members of the cultural group (Roper & Shapira, 2000).

3.2 Focused Ethnography

The type of questions that nurses ask which require ethnographic methods usually focus on a specific phenomenon that affects health or wellbeing within a larger unique context or culture; therefore, it is appropriate to choose focused ethnography to explore relationships among those in a broader culture i.e. Northern Ghana who are affected in one way or another by a particular circumstance such as providing support for a woman who experiences OF (Roper & Shapira, 2000). Focused ethnographies differ from other ethnographic designs in that they are used to explore a subculture, and may be completed in a shorter time frame as the research question is formulated prior to entering the field (Streubert & Carpenter, 2011). As a result focused ethnography was the research methodology that was best suited for this study in that the research question was formulated prior to the commencement of fieldwork, the time in the research setting was limited and the research questioned focused on the distinct phenomenon of support for women affected by the condition through those closest to them. Leininger & McFarland (2002) suggests nurses are natural ethnographers. In their daily practice, nurses seek to understand the people they care for in order to better assist them in addressing their healthcare needs. Nurses use their expert assessment skills to collect information by observing and interacting with their clients (Fontanie, 2009). One of the central aims of a focused ethnography is to describe emic insights regarding the phenomenon so these observations can be used to improve practice. For nurses, this usually involves developing interventions to promote holistic health and healing based on insider knowledge.

3.3 Setting

The setting for this research study was the metropolis of Tamale, the capital city of the Northern Region of Ghana, West Africa. In terms of landmass, this region is the largest of the ten geographic regions in the country and it is home to a diverse group of peoples with distinct ethnic backgrounds who speak many different languages (Government of Ghana, 2013). Currently the region has a population of 1,820,806, which represents approximately 9.6 percent of the total population of Ghana (Government of Ghana, 2013). Culturally, spiritually, linguistically, climatically, and economically, the Northern Region differs greatly from the South and Central regions of the country (Government of Ghana, 2013). Ghana's Northern Region is predominantly savanna grassland and does not have the large reservoirs of natural resources found in the forested South (EngenderHealth, 2004). As a result, there are fewer economic opportunities in the Northern Region, thus the region is far less developed; the healthcare system mirrors this difference. For example, there are approximately 100 OB/GYNs that practice in the country but only three who practice in the North (EngenderHealth, 2004).

According to the Ghana Health Service (2012) Annual Health Report, the Northern Region of Ghana recorded the presence of skilled attendants at only 31% of births. This percentage indicates that more women deliver at home in unsupervised birthing settings. The lack of skilled attendants and resources may contribute to the Northern Region being home to the largest proportion of women living with OF in the country. According to the Engender Health (2004) needs assessment, it is reported that, nearly 70% of diagnosed cases of OF in Ghana are found in the Northern Region, with approximately one case occurring in every 1000 live births.

In the rural areas of these deprived regions, access to healthcare is limited and most of health facilities (hospitals, maternity care homes, district health clinics) are located far away from rural villages or community settlements (Danso, Opare-Addo, & Turpin, 2007; Mwini-Nyaledzigbor et al., 2013). In addition, only 45% of the road network is tarred and most villages and settlements can only be accessed via roads and footpaths that are impassable by vehicles. Due to a shortage of skilled birth assistance and a lack of proximity to facilities, most of the population of the Northern Region has very limited access to healthcare.

The Northern Region is divided into 26 health districts. Tamale, the commercial and cultural centre of the region, has three hospitals, including one teaching hospital and two government hospitals. This region has an OF treatment centre located in the Tamale Central Hospital, a government facility. The Tamale Fistula Centre (TFC) undertakes the repair and treatment of women with OF, serving residents of the three Northern Regions, Upper East, Upper West and the Tamale Metropolis as well as women from neighboring Burkina Faso and Mali. Thus, the TFC was selected as the primary research site for data collection for this study. The TFC is a stand-alone structure located on the grounds of the Tamale Central Hospital; however, the TFC functions as its own entity. The TFC consists of a small operating theatre, a physician's office, and an eleven-bed ward. The primary research site was the eleven-bed ward but occasional observations and informal conversations were conducted outside the operating theatre, in the physician's office, outside the building on the hospital grounds, and in villages surrounding Tamale.

The TFC was created in partnership with the UNFPA in response to the high prevalence of OF found within the Northern Region. The centre was inaugurated in 2009, with the support of UNFPA funds; however, the TFC has since become the responsibility of Ghana Health

Services. The director of the TFC is an obstetrician/gynecologist with a specialization as a fistula surgeon. Aside from the director, approximately ten to fifteen nurses work at the TFC. Permanent nursing staff is not employed directly by the centre but rather through the Central Hospital. As a result, members of the nursing staff do not have any formal training in providing appropriate care for women with OF.

Although this site was designated as fistula treatment centre, repair surgeries are conducted on a semi-sporadic basis. When the clinic is not functioning as an OF repair centre, the facility operates in a way similar to that of a obstetrics and gynecological clinic where the centre's director performs other gynecological procedures for women including Cesarean sections, mammectomies, hysterectomies, and other obstetrical and gynecological procedures. To date, there have been approximately 350 OF repair surgeries performed at the TFC (Gandau, 2013 personal communication). However, in recent years the number of surgeries conducted at the TFC has been decreasing and the reason for that is largely the result of lack of funding and qualified staff.

3.4 Sample

When conducting an ethnographic study, the sample is often drawn from the community in which the researcher enters (Fetterman, 1998). The community for this study included women who have or have had an OF, and those close to these women (spouses, partners, friends, mothers, mothers-in-law, healthcare providers.). This community was found at the TFC and in three selected villages where women experiencing OF reside within the Northern Region. In research using ethnographic designs it is essential to identify key informants and gatekeepers in order to gain access to the community the researcher enters. With the guidance and assistance of a key informant, Mrs. Priscilla Naa Boakye, the researcher was able to establish a rapport with the community gatekeepers. Gatekeepers included the director of the Tamale Fistula Centre, a traditional birth attendant, and village health workers. Mrs. Naa Boakye is a nurse-midwife enrolled in a Masters of Philosophy graduate nursing program. She is familiar with the culture and has lived in the Northern Region all of her life. Mrs. Naa Boakye facilitated the process of gaining access to the research site by introducing the researcher to the appropriate administrators and by accompanying the researcher on her first visit to the TFC. Initially, the researcher began as a non-participant observer at the TFC. During this period she observed those associated with the TFC including their interactions, activities, rituals and physical environment. The researcher engaged in informal conversations with a variety of insiders (both staff and visitors), and kept a diary that described what she learned and her response to that information. This was done using a voice-recording device. This initial phase of entering the community and becoming familiar with TFC patients, family and staff, and observing the formal and informal relationships amongst them, assisted the researcher in recruiting the targeted sample to participate in formal interviews for the study.

It was anticipated that the sample recruited to participate in focused interviews would be primarily Ghanaian men who have, or had, a wife/partner who either has OF or has had an OF repair. However, consistent with a focused ethnographic design, individuals other than husbands/partners were encouraged to participate as they too could provide important insights into understanding the phenomenon of support available to women who experienced OF with or without treatment. In this particular research study, women with OF, women who had had an OF repair, surgeons, nurses, parents, partners and other family members participated in formal interviews. Traditional birth attendants, community health workers, community members, and visiting volunteer healthcare professionals were observed in their environment while conducting their activities; many also participated in informal interviews.

The recruitment strategy for the formal interviews was purposive. In qualitative research, purposive sampling allows the researcher to choose participants believed to be the most knowledgeable about the cultural group and who are able to provide key insights into the phenomenon of interest (Roper & Shapira, 2000). Key informants, nurse midwives practicing at the TFC, assisted in identifying those who were potentially interested in talking with the researcher. Since the researcher was not able to speak the local language, the first point of contact for participants was through a key informant or translator. The translator explained the study details to potential participants, and explained the information letter in the local language (Appendix E). A small honorarium was provided to those who formally enrolled in the study. The amount of the honorarium was discussed with the members of the local research ethics review board in the region; the decided amount was based on those recommendations. The honorarium was determined to be one bar of key soap and one 250-millilitre bottle of a disinfectant (Dettol). This decided amount was deemed sufficient to compensate the participant for the time taken to speak with the researcher but not large enough to be considered coercive.

Congruent with qualitative methodology, the sample size for the proposed study could not be determined *a priori.* However, the sample size had to be large enough so that it was possible to identify themes and concepts within the data set. The primary goal of this study was to increase understanding of the phenomenon of support for women experiencing OF in the context of Northern Ghana; therefore, participants were carefully and purposively selected mainly from the TFC. In this research study, 14 individual interviews were conducted. Participants included: women living with OF awaiting repair surgery, women who already had surgery to repair OF, partners of OF patients, parents, relatives, nurses and doctors. All participants were given oral and written information about the study and only those who gave their informed consent were interviewed. Data collection continued until no new information appeared to be forthcoming, or in other words, when the researcher believed she was not learning anything new by continuing the interviews.

3.5 Data Collection

The techniques of non-participant observation of those at and around the TFC, conducting formal interviews, and examining relevant documents were used for data collection. The researcher was the key instrument for data collection. Data collection occurred primarily at the TFC and this decision was made in conjunction with Ghanaian colleagues in the Northern Region. Prior to conducting any formal interviews, the researcher initially spent time at the TFC, focusing on observing participants in their natural setting. This initial phase allowed time for the participants to be comfortable with the researcher's presence at the TFC. It also provided an opportunity for the researcher to gain an understanding of how the TFC functioned. During this time the researcher had the opportunity to ask her Ghanaian contacts about behaviours and practices that she had observed.

During this exploratory phase, the researcher compiled field notes describing what she saw and her response to what she experienced. Notes included observations of women admitted to the TFC, individuals who visited the women, how those involved interacted with eachother and descriptions of the physical environment (Martin, 2009; Roper & Shapira, 2000). Field notes were organized systematically and included dates, times and locations. Entries were organized into two columns, one describing the conversation and/or observation, and the other designated to describe the researcher's reactions and the analytic inferences she drew from the observation.

To ensure the completeness and accuracy of her field notes, the researcher utilized the strategy outlined by Strauss & Corbin (1990), ensuring that all comments that were made directly from the participants were placed in quotation marks. When the researcher paraphrased participants' comments, a single apostrophe was used. In cases where the researcher had less accurate recall, for example, several hours after the observation or conversation, no marks were utilized (Strauss & Corbin, 1990). Field notes were recorded daily at the TFC using a note pad and paper. Furthermore, complete field notes were recorded at the end of each day after the researcher had left the TFC. These notes were usually documented using a voice recorder and then later transcribed verbatim into text. Field notes were reviewed daily.

Data were initially collected by conducting loosely structured interviews with purposefully selected participants. These interviews were conducted in a location according to participant preference. Semi-structured interviews using open-ended questions were not conducted until later, approximately two weeks after entering the research setting. This allowed time for the researcher to develop a greater understanding of the themes that were developing and allowed time for the researcher to gain entrée into the community.

The semi-structured interviews were conducted as another data collection method. The participants were offered the option of conducting the interview in English or their local language. When participants preferred to speak in their native language, a translator, who had signed an oath of confidentiality, was present at the interview. When it was feasible, a male was recruited to translate conversations with men and a woman served this function for the women. Mrs. Naa Boakye recommended the appropriate remuneration for the translators. The interview guide was refined as new themes started to emerge and different participants were selected. Examples of interview questions are presented in Appendix E.

Participants were interviewed at least one time; however, all participants had the option of participating in up to three interviews. Although no consecutive formal interviews were conducted the researcher did engage in informal conversations with participants when data clarification was required. The interview length was expected to last approximately one hour. Actual interview times ranged from thirty minutes to one hour and twenty minutes. All planned interviews were audio recorded and immediately after the interview, the researcher recorded notes describing non-verbal cues that she observed during the interview. Audio-recorded data were then transcribed verbatim. When it was necessary to conduct interviews in a language other than English, the translator translated the participant's responses to English as close to verbatim as possible. Following the interview, the translation into English was transcribed. To confirm the accuracy of the translation, a Ghanaian graduate student listened to three selected translated interviews to confirm whether they agreed with the accuracy. Interviews took place in private, mutually agreed upon locations, typically in participant's homes, in quiet areas on the unit at the TFC, in the physician's office or outside in a shaded, quiet area. In addition, all interviews were retained in their entirety. This is a way of confirming correct translations and allowing for the possibility of conducting a secondary analysis in the future.

To gain further insight into the context in which support for those experiencing OF occurs, the researcher traveled to three villages where there were known recorded cases of OF. With the assistance of Mrs. Naa Boakye and the community health nurses in the village, the researcher had the opportunity to meet and interact with village members. During this period, the researcher observed community members in their interactions, activities, rituals and living environments. Visiting a variety of clinics, schools and traditional homes provided the researcher with insights into the social life of those living in the North.

In the village the researcher has the opportunity to visit the home of a traditional birth attendant (TBA). The TBA revealed where she ‘caught babies’ and the instruments in which she used to assist women during labour. While visiting the TBA in her home the researcher was able to in engage in variety of informal conversations. Conversations focused on the awareness of OF in the community and where the majority women in the community choose to give birth. Visiting the maternity clinics and observing an antenatal clinic in the village provided insights into the environment in which women in these rural communities give birth and the services available to them. Time spent in villages contributed to capturing a more comprehensive picture of OF; time spent observing and interacting with community members assisted the researcher in providing important insights to increase understanding of this phenomenon (Roper & Shapira, 2000).

The last method of data collection used by the researcher was the examination of existing documents. This included an audit of anonymous census data, health charts and other relevant cultural artifacts. Educational materials on the post-operative care and teaching for women and families following OF surgery were available to the researcher. Considering the process of ethnography is a comprehensive appraisal of a particular phenomenon, examination of special cultural artifacts and places, helps the researcher understand the culture in which the phenomenon occurs. The researcher was also able to visit important cultural attractions, such as the site of the sacred tree, an ancient mosque and a cultural museum.

3.6 Data Analysis

Ethnographic methods require that data collection and analysis occur simultaneously. As data were obtained, they were compared to data already collected and used to determine subsequent data collection activities. The data analysis process described by Roper & Shapira (2000) was utilized. This is a non-linear process that includes coding of the field notes, sorting to identify patterns, and theorizing to create conceptual models or creation of data matrices. Data collected from observations, interviews, field notes were combined to create descriptive labels and were used to create data clusters. Key words were underlined and patterns were identified, all of which became codes. Descriptive labels were created in order to sort through patterns in the data. This allowed for an initial sorting of the data to identify patterns and themes, while simultaneously looking for comparisons and contrasts (Roper & Shapira, 2000). The researcher used this understanding to direct the remaining data collection processes.

Throughout the research process, the researcher recorded reflective insights gained from the data and her experience. This is a process known as memoing (Roper & Shapira, 2000). These memos were often in the form of questions or ideas that emerged from the researcher's experience of immersing herself in the culture and context. Memos were distinguished from the data by documenting these reflections in a separate section of the field notes.

3.7 Rigour

To ensure this study was conducted as rigorously as possible, there were several significant considerations. The systematic process of triangulation is inherent in ethnographic designs, and this supported the trustworthiness or the validity of this study's findings (Roper & Shapira, 2000). Ethnographers observe situations as they occur in a natural setting; however, the presence of a researcher in the natural setting has the potential to affect the behaviours of participants (Roper & Shapira, 2000). To appease the researcher, participants may respond to what they believe is most acceptable, or in the most socially desirable way (Roper & Shapira, 2000). To address this challenge, the researcher spent time in the study setting before initiating the data collection, to allow participants the opportunity to become accustomed to her presence. Once data collection commenced, the researcher gathered information from observations, interviews and documents, constantly comparing and contrasting the information she complied from one method to the next.

Data collection methods must be transparent to enable other researchers to follow initial decision trails or replicate the study (Roper & Shapira, 2000). To maintain rigor, the researcher created an audit trail, documenting all decisions made throughout the study. To ensure others could follow the researcher's decision process, her supervisor was provided with interview transcripts to confirm that the data analysis was logical and reasonable (Fontaine, 2009).

Ethnographers are intimately engaged with study participants, so they must attend to the concept of reflexivity so that they can support the rigor of their study. In order to ensure reflexivity, the researcher must have a clear understanding and awareness of how she may affect both the research process and analysis. In order to ensure reflexivity, a private journal, separate from the field notes, was maintained throughout the study. In this journal the researcher engaged in self-examination in order to understand how her own values, beliefs, preconceptions and culture may be impacting the research process. Acknowledging this concept of reflexivity is necessary in order to enhance the rigor of qualitative research.

3.8 Ethical Considerations

Conducting an ethnographic study with partners and relatives of women who have suffered from OF has significant ethical implications; therefore it is imperative that the researcher subscribes to the code of ethics clearly outlined in the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS) as well as similar policies developed in Ghana. Such codes were addressed, considered and upheld through the proposal development, conduct of research, and analysis of the findings. They will be upheld for dissemination of the findings. The researcher submitted proposals to the Health Review Ethics Board – Panel B, University of Alberta and the Navrongo Research Unit, Navrongo, Ghana and site approval was granted by the director at the TFC. All proposals were approved by research review and institutional committees prior to study commencement.

Significant ethical issues could arise as a result of the study setting and the sensitive nature of the research topic. As the researcher is not Ghanaian, the issue of insider versus outsider perspective had to be addressed. Attempting to acknowledge this issue, the researcher worked in partnership with Ghanaian scholars and community representatives. Throughout all stages of the research process, the researcher sought insight and guidance from key informants and team members. These contacts were available to her through already established contacts at the School of Nursing, University of Ghana and in Tamale (close to data collection sites).

Protecting the privacy and ensuring the confidentiality of all participants involved in the study was imperative. To insure this, names of those observed were not recorded. The purpose of the study was clearly explained to every participant. Each participant was encouraged to ask questions so that they completely understood the nature of the study and how findings would be disseminated. A written informed consent from each participant was obtained and witnessed at the initial meeting. Language considerations were accounted for in that a translator was available for those wishing to speak a language other than English. For participants who were illiterate, the researcher or translator read the consent and ensured they had understood its contents and any potential implications. For participants who were unable to write, a witness not involved in the study observed the marking of a thumbprint as a proxy for the participant’s signature. Informed consent was obtained voluntarily and it was explained that any participant was free to withdraw from the study at any time during the conduct of the research. Further, it was explained to participants that no one would know whether or not they chose to withdraw from the study unless they chose to tell him/her. This applied to everyone (aside from the translator who was bound by the confidentiality agreement). Due to the sheer number of different languages and dialects spoken by the participants, consent forms were not translated, but rather were explained in the local language by the translator and confirmed by a nurse or staff member who was also fluent in that language.

To ensure confidentiality throughout the study, identifying information was kept in a secure site separate from the data. Every effort will be made to not inadvertently profile participants by linking quotes and demographic characteristics. All data was kept locked in secure storage; further USB keys and the laptop computer used by the researcher were password protected and kept locked. Consent forms were kept locked and separate from the data to ensure anonymity was maintained. The transcribers and translators were required to sign an oath of confidentiality. Upon completion of the research, the data will be kept in a locked cabinet at the University of Alberta and will be retained there for at least five years. A summary of the researcher's findings will be provided to the University of Ghana and the health sub-district in which the data collection took place.

Chapter 4

Results

The data collection methods utilized in this research study included non-participant observation, informal and formal interviews, and examination of relevant documents. Major themes were identified in the data, which provided insight into the types of support perceived to Ghanaian women who were currently living with OF or had dealt with an OF repair in the past as well as perception of support by those close to them.

4.1 Characteristics of the Sample

A total of 14 people participated in formal interviews. Sample size was based on informational need and data saturation. Participants included: women who were awaiting fistula repair surgery; women who had already had a fistula repair surgery; spouses/partners, parents, and other relatives of women with fistula; and healthcare practitioners (nurses, nurse-midwives and doctors). Three women were awaiting fistula repair surgery, two women had already had the repair treatment although one of these women described her surgery as unsuccessful and as a result returned to the TFC in hopes of having another surgery. A total of four dyads were interviewed which included father-daughter, mother-daughter, and spouse (woman affected by OF)-spouse groups.

Most of the participants did not know their age, so they based their age on estimates. All except one participant lived in the Northern Region, yet most came from different tribes. Though the majority lived in the North, they spoke a variety of languages and dialects. Islam is the predominant religion practiced in the North; however, in this study the majority of participants identified themselves as Christians.

The predominance of women who arrived at the TFC had suffered from vesicovaginal fistula (VVF) and rectovaginal fistula (RVF) as a result of obstructed labour; although, in one instance a woman had acquired a fistula as a complication of a uterine fibroid removal surgery. Often women based their age on estimates which and ranged from 25 to 46 years of age. Typically the women did not have a spouse or partner present at the clinic. With the exception of one participant, all women were married before the development of OF. Several women stated that they were no longer married after developing the condition while others explained that they did have a husband but that he was at home. Few women had children as the majority experienced the death of their babies due to prolonged labour.

Often, women who arrived at the TFC were accompanied by a family member, friend or relative. Women and their families often arrived at the TFC from villages outside Tamale. Although the actual geographic distance was usually not far, the poor infrastructure and fragile road network resulted in the journey taking many hours and, in several cases, days. Farming was the predominant occupation of women and family members who were interviewed. Others were involved in petty trading, brewing pito (local beer), and head portering (conveying heavy loads on their head). Despite their past occupations, at the time of the interview none of the women were working.

4.2 Thematic Findings

Insights from the data collection process revealed a number of emerging themes, which provided a description of the types of support perceived by women living with OF or who had lived with OF in the past. Major themes represent broader ideas while categories and subcategories are more precise. The following text includes sample narrations from the participants that support the highlighted themes. Names and other identifying information were not included to insure participant anonymity. Narrations were recorded verbatim, however in rare instances, due to the way the interview was translated, some narrations were changed to first person singular.

4.2.1 Tangible support through unbreakable family ties. Family ties and lineage are extremely important facets of Ghanaian culture. Ghanaians view family as a source of identity and pride and achieve a social standing based on their family size. Family sizes are typically very large as extended family members and relatives are all considered members of one’s immediate family. For Ghanaians, a familial connection is perhaps the strongest bond a person can have and one that is not easily broken. As a result, several women with OF receive support from their family members and extended family. One local healthcare professional explained the responsibility family members feel in terms of providing support to women who have OF. A nurse said:

> You know, luckily in Ghana, in general, in Northern Ghana in particular, many people do not lose their family touch easily. Many of them [Women with OF] maintain, the family contact. It may not really be their matrimonial family or their marital homes, but even they are there.

Most participants who experienced OF reported that it was their parents who were the most supportive, particularly their fathers. Women described this support as mainly economic, providing for their basic needs such as food, clothing, and money for soap. Often it was the parents who provided these women with money for transportation to get to the TFC. One woman described the support she received from her father:

> Um, it's my dad who helps me to get to this place. My mother is deceased and my husband says he hasn't got money to care for me, to spend on my treatment, so I had to go to my parents, and for him, even before I had the condition, he said he wasn't interested in the marriage, so before I even had a condition, he had problems, and after the condition it was worse and said he hasn't got money to pay for my, the course of my treatment, so I should go. So I left for my dad's house.

4.2.1.1 I couldn't "Throw her away." In many Ghanaian cultures it is believed to be dishonourable to neglect your child. In most cases, when a woman loses the support of her husband after acquiring a fistula, the responsibility of caring for her falls to her parents. As a result, parents feel they have no other option but to support their child. Similarly to the experience highlighted above, another woman was also told by her husband that he was "not interested" in the marriage anymore and that she should go stay in her father's house. Her father explained the responsibility he felt in accompanying his daughter to the TFC and in ensuring that she received treatment:

> How can I throw my own daughter away? That is [his wifes's] child and if I throw her away and if any other child of his who falls sick I have to take care of that child too. So I cannot throw a child away. That is because of the sonship, the daughtership, I cannot throw the child away. It is my child. (Father)

To further highlight the responsibility parents feel, a mother of one of the woman at the TFC explained:

> She's my daughter and I love her. I can't throw her away and that is why I had to do it. If I don't do it, who do you expect to do it? (Mother)

Typically the women, especially those who had lived with a fistula for a longer period of time, were no longer married, or they were married but no longer living with their husbands. As a result, other family members accompanied these women to the TFC. A local nurse-midwife who has been working in the area of OF for several years explained her experience in terms of who she sees accompany women to the fistula repair surgery. Her interview highlighted that in most circumstances, even if a woman states that she has a husband, they often do not accompany their wives, nor do any members of his family. She said:

> Most of the time it's the clients relatives that come with them, but wherever she went and have the problem, that's the husband's home, most of the time they don't come. (Nurse-Midwife)

4.2.1.2 "I feel pity." Family members of women with OF described in detail the pity and sadness they felt for their daughter/wife/relative/friend. For example, the following exemplars highlight the pity parents felt for their daughters after they developed OF**:**

> In fact, when I got to know that my daughter had this, could not control her urine, could not…every time she's lying down she's wet, she's walking, urine is trickling…I felt pity for her. I said [Mmm] what kind of illness is this? How can she be wetting herself all over? I felt so pity for her. (Father)

> I feel pity for my daughter because this kind of illness, if it affects a human being, you are no…you become anything. You just become anything and in our tradition, when you are walking and urine is flowing like that, uncontrollably, you are seen as an unclean person. (Mother)

Not only were parents sympathetic to their daughters but spouses also reported feeling pity towards their wives. For example, a husband explained the worry he feels since his wife developed an OF:

> And I get so worried when I go to sleep; I have been thinking and thinking and thinking. Sometimes I think all through the night because a woman, my wife who is pregnant, only to go and deliver and come back with this condition, I sometimes feel pain within me because I can't imagine a woman who cannot go to places because you don't expect... A woman shouldn't go to a place, sit down and the chair is wet and nobody can go and see that. And I can't imagine you going to public places and you are always wet and smelly urine; it's not fun. (Husband)

4.3 Spousal Support

Similar to family ties, marital ties are also very important in Ghanaian cultures. For a Ghanaian, marriage is a very crucial milestone. Particularly in the Northern Region of Ghana, marriage often occurs at a young age, around eighteen or nineteen years. The decision to marry is usually based on strong recommendations from one's family and community.

The women who participated in the study typically reported that they had continued to be married after acquiring an OF. Many of the women reported that although they remained married, they often did not live in the same house as their spouse. A nurse involved in working with OF outreach programs explained her experience in regards to what she witnessed in the communities:

> In the communities, most of the time, even if they are in their husband's houses they are separated. They will have their own room, nobody goes there, they don't take part in any activity in the house. They are always alone, and then some don't even stay in that house. They will move outside and rent a place, or if somebody around has a free room, they can give it to that person to stay in it. (Nurse-Midwife)

One participant, who was waiting to have the fistula repair surgery, explained that she was still with her husband but they had decided that she should go and live with her parents until she had her surgery. She further explained that it would not be until after the surgery that she would go back to her husband's house.

> Well, you know, he's a man and definitely he should have interest in sleeping with his wife, but he's been so supportive. So I told him that the way it is, it's an agreement between the two of us that I'll go and live with my parents, so that when I get well, he can [unintelligible]. I don't want to be in his presence and then he has an interest and yet he cannot sleep with me and all this, because… But it's not that we had any problem, no, it's not that too. We agreed so that at least to be in a room and you are smelling and all those things, is making your husband uncomfortable, so I agreed I'd go and live with my parents and he also agreed.

Although, many husbands did not accompany their wives to the TFC, there were cases where the husband did follow. For the rare women whose husbands were present at the clinic this comment was typical:

> He's been so supportive; so he's been with me throughout these three months all the time, almost all the time. He's been with me throughout.

A woman who had already had her fistula repair surgery explained that she felt it was her husband and sister who helped her in accessing the repair treatment. She explained:

> It is my husband and my younger sister that have been so supportive and helpful.

4.3.1 "She is my wife." Women's partners occasionally stayed with them after they developed an OF. In these instances, a husband would typically report that he felt responsible for his wife and felt he needed to help her 'during her bad time.' One husband described his appreciation for his wife's hard work and explained how this contributed to his motivation for accompanying her to the TFC:

> I have been with her all through, married her, we have children. She gives

> and we live very happily, I must say that. She has not done any evil to me; she has been very supportive and I can't say because of the illness I just dump her here at the hospital and leave her to care or fend for herself. She helps me a lot in my farm activity, she works like I work. Sometimes I have to tell her she's tired so she just stay away and I work. She's not a lazy person; she's so hardworking, so committed, and that is why I'm still standing by her in this difficult moment of hers.

He cited some advice he received as a young boy as the rationale for continuing to support his wife, despite her having developed an OF:

> Now you know what, my grandfather when I was small and green, my grandfather used to tell me that if you want to be happy in this world stay with your wife. If you get married, be faithful to that wife, stay with her all through, and that has been my guiding principle.

When asked about what advice he would give to other husbands whose wives have OF he said:

> For me, I think that every man should support his wife. Every man should be with his wife, his wife who develops this condition. And it will not be fair for a woman, your wife to develop this condition and we just abandon her and go away. You have to be with her. Are you trying to say that you only love her when she never had a condition and when she developed the condition you wouldn't love her again? For me, I think all men should support their wives, at least provide her with food, make sure that they don't lack. If it's not even there, try and go and work harder to enable you to get something and bring to them. No man should stay away from his wife; be with her throughout, because you married her. Why should she fall sick? If you fall sick will she leave you?

Another husband who arrived at the TFC described his relationship with his wife and he explained that he continues to do all the things he used to do for his wife, despite her condition.

> Yeah, we are okay. We have a good relationship because I have been with her all through, whatever she requests for I provide. I got to the hospital with her any time; we are going to see the doctor. I am always around. And I'll do everything just as I used to do for.

4.4 Lack of Support

Most participants reported experiencing a loss of support from someone close to them after developing a fistula. Most often it was a spouse or partner that tended to withdraw support, particularly emotional support. Participants reported experiences of abandonment when their husbands became "fed up" with the situation and no longer wished to continue the marriage. A young woman who had been living with her OF condition for several years explained that not long after she acquired her fistula, her husband asked her to leave:

> So I was still then with my husband and then he sent me around for treatment and he later became fed up [when I was not cured], so he left me lying down in the room.

Similarly, another women described her experience of losing the support of her husband not long after she developed a fistula:

> So, let me say that when I left [village], like I told you earlier I left [village] to my village. My husband said he's not going to follow me, I should go because I am carrying some illness, and for that matter I should go. He doesn't want me near him.

4.4.1 I was left "on my own."

Before arriving at the TFC, participants described spending the majority of their time alone. As a result of OF, they had very little involvement in family and community gatherings. Moreover, two women reported to having no support person before coming to Tamale, nor while staying and waiting for treatment. One woman said:

> I came alone, all by myself. I was not accompanied by anyone. (Woman with OF)

The other said,

> I stayed there and I was feeding and cooking on my own. (Woman with OF)

At the TFC, surgery times and dates were not predictable and as a result women waited for long periods of time in hopes of getting the surgery. Another participant who was waiting to have her second fistula repair surgery (her first surgery was not successful) described her previous experience at the TFC, particularly that of waiting for the doctors to arrive:

> I was living here alone, then when I was about to have the surgery, I sent a message that my sister should come…I stayed here alone and was feeding and cooking on my own until the doctors came.

Observation data further revealed the types of support provided to women at the TFC. Generally, women received little overt or obvious support while at the clinic. Although many women arrived at the Tamale Fistula Centre accompanied by a family member or relative, often these relatives would drop the women off and return back to their villages, leaving the woman to stay at the clinic by themselves. While at the TFC, many women experienced difficulty meeting their basic needs because very few resources are provided to them. For example, food and washing materials are not provided to patients and many women go without food for days and even weeks. Usually the women who arrived at the TFC were not aware that they would need to stay for a long period of time. Not being familiar with formal medical procedures, these patients did not realize that they would have to stay for several days prior to and following surgery. Frequently women would arrive unprepared with no food, clothes or washing supplies for their stay. If family members were able to afford it, they provided small foodstuffs such as rice, beans and millet. Those women who did not have a relative or whose family could not afford to buy food had to then rely on the support of other women or the nurses and staff at the TFC. Nurses working at the clinic would sometimes give women little bits of food that they had prepared and were eating at the clinic. In addition, sometimes volunteer doctors and staff donated money to purchase required medications for women who were not able to afford them (i.e. antibiotics, anti-inflammatories).

4.5 Spiritual Support

Religion and spirituality are also crucial components of Ghanaian culture and part of everyday life. For Ghanaians, religion is an important feature of both public and private life. Although, there are several different religions practiced in the country, everyone seems to belong to one religion or another. As one key informant highlighted:

> You virtually would not be able to find one Ghanaian who does not believe in God. (Informant)

4.5.1 "We prayed." Spirituality, and the belief in God was reported to be an important coping strategy for women and family members. Spiritually based coping strategies practiced by women and their families at the TFC included: praying, chanting, performing ablutions and holding consultations with 'the Gods'. In many cases women reported that it was their belief and trust in God that helped them through their difficult situation. An example of a participant's account of her belief was described as:

> I just trusted God that everything would be well for me.

Similarly, another woman reported,

> Well, I just gave everything to God.

It was not only the women who reported this type of spiritual coping; spouses, and other family members also described their spirituality as a way to face difficult situations. Participants' accounts of these strategies are described in the following exemplars:

> Well, we've been talking about it and praying together because we kept praying, hoping that God will open the way for us to get, refer her from the hospital and then God will also, praying that God will open the way to get a doctor who treats her of this condition. So we kept on praying and praying and praying and when they said they were going to refer her to Tamale but the doctor who was to do that wasn't around. (Husband).

Generally, women and relatives did not know what caused the fistula but they felt that 'whatever happened' was the will of God. When asked about what he believed was the cause of his wife's OF, one husband reported:

> Well, that one I cannot tell because I just know that anything that happens is from God, so I really cannot say what has caused it. I just know this is the will of God so really I'm just affected by that.

Many participants believed that healing could occur through God by the means of prayer. One relative reported his rationale for initially sending his sister-in-law to a prayer camps after she developed OF:

> Yes because we believe that something can be done that way and God is the main key to everything So we send her for the prayers camp and she was with all that suffering. (Relative)

Another husband shared his advice as to what other men should do in the event that their wife developed an OF:

> Our advice, all other men who will have…in case their wife should get this condition, they should give everything to God. And I'm also going through with it, I know how it is, but they should trust God and always take instructions from the doctor.

Women and families also appeared to have received support from organized religious groups. In particular, several women reported that it was their church congregations and priests or ministers, who assisted them by providing money to get to Tamale. One participant reported her confidence in her Reverend Father after she developed the condition:

> Then I decided that I will go to my church, to talk to my pastors and when I met one Reverend Father, I told him that this was a condition that is worrying me. So I was there and we, the pastors were praying, praying, praying, praying. Then one day, I was just there when the pastors sent that I should, they should come and call. So I went and the pastor said, the next day we are going to Tamale.

In her case it was this Revered Father who accompanied her back home to her village after she had the OF repair surgery.

4.6 Economic Support

In general, when participants were asked about the support they received, they usually referred to economic support. Often it was the woman's family and relatives that pooled resources so that she would be able to travel to the TFC. As one woman reported, it was her father-in-law who assisted her in providing sufficient funds so that she would be able to receive treatment and surgery:

> My father in law has been so supportive. He was so disturbed; everybody in the house – my husband's brothers – they are so disturbed. And even my father-in-law went and told the doctor whatever you do to make sure that I get healed and treated of this condition, the doctor should do it and whatever it would take him, they will be ready to pay for whatever it is.

When woman and families could not afford the cost of travelling to Tamale for treatment they would often reach out and ask for the assistance of friends and members of their community. Participants described the community economic support they received as follows:

> In fact they became also…they felt so pity and said, what kind of illness is this? So they said what they could do was to assist me with some money to get to Tamale, because they were so sad to see this kind of illness in our family. (Mother)

> Everybody seems to brew Pito and we are alike in our situation, so those people come to share sympathy with me and then when they also come they contribute us small amounts to assist me to get to this place. (Mother)

4.6.1 "The pocket is dry." All of the women in the study had not been able to work after developing a fistula. This loss of their livelihood forced women to rely solely on their families for economic support. At the same time, many families were already experiencing financial strain and often did not have funds to meet their basic needs. Meanwhile, the costs associated with having a family member with OF often sank families into deepening poverty (cost of treatment, soap, transport to and from healthcare facilities and hidden hospitals fees). One of the women described her family's struggle to find resources for her to travel to the TFC:

> So I told my dad that I had a message that I had to come to Tamale, they had called that I should come to Tamale. When I told my dad, my dad said he has no money because they assisted me throughout the time I was ill and they ran out of money, so they don't have money to assist me. Then I was there and when the date was getting nearer, I went back again to tell them that, Dad, it's time for me to go to Tamale. My dad said he hasn't got the money so, and he cannot get money for me to come. So I went to the Reverend Father, the pastor who assisted me earlier. When I got there, they said he had traveled, and so I came back and told one of my father's younger brother, if you could assist me with money. He said, where can he get the money for me? He hasn't got the money, then I said, if he could give me something so that when I come back, when I come to Tamale, and I return, I'll get some, if I get some money I'll pay him back. And he gave me the money and my dad too, support him with a little money and that is what has brought me to Tamale.

A father of one of the other women at the TFC tells of how his daughter's condition affected his finances and his ability to concentrate on his work:

> I am saying that it has affected me in the way that um my money I have been using I is sending the child to the hospital. I sent her to [Village] first and the money I was using here the same thing and because of my up and down movement the farm it . . . could not . . . I could not concentrate on the farm very well.

4.6.2 She was "spending a lot." Several participants did not receive any financial assistance from either their spouses or family members. One women reported losing her job as a result of acquiring an OF and she had no one to support her financially. This woman ended up spending the little resources she had on things like soap and detergent. As her relative reports:

> She suffers from urine, the way it is flowing. It's not much like that like, but for her it's someone who doesn't like dirt. So even if she buys soap today, it will not reach her, so that is suffering. Then she start to lose, not easy to do anything, and she's spending a lot actually, spending a lot. (Relative)

4.7. Formal and Informal Healthcare Provider Support

4.7.1. Lack of access. Almost of all of the women at the TFC had been in contact with the formal healthcare system before coming to Tamale. Often it was the detrimental physical effects caused by the fistula (leaking urine/feces, pain, infection) that motivated women and families to seek this treatment. In several instances, women sought the care of a traditional healer before accessing formal care. Rationale for seeking traditional medicine was largely due to the location of the traditional healers and the cost. Many healers lived within the same community and the cost of their services was significantly less than the cost of orthodox treatment; moreover, women would not have to pay for the cost of travelling to a hospital or clinic. After coming home from the hospital and having lost her baby, one participant tells of the events that followed:

> So when I got home from the hospital, they were taking care of me at home and I was living with my husband and his relatives, but I became very ill. I could not walk, I could not stand, so my dad came and pick[ed] me to a herbalist and he applied some herbal preparations on my legs. So I was given the herbal preparation to apply on my legs and it subsided so I returned back to my husband's house, though I was better. But the urine flow hasn't stopped, so I had to leave for my dad's house and then he took me to church and that's how come I met the pastor and he took up the responsibility to bring me to the hospital.

Often, when it became apparent that the use of traditional medicines was not adequate to cure the condition of 'leaking urine,' women would resort to seeking medical care at a hospital or clinic. As previously reported, the majority of women had been to a hospital (often a district or regional centre) before arriving at the TFC. Women shared accounts of arriving at hospitals and being told that "there is nothing we can do for you here." Women expressed frustration and dissatisfaction with the services and care provided at hospitals. For example, one woman explained that she was transferred to three different hospitals before a doctor told her that there was nothing they could do for her. She described her frustrations thusly:

> I can't even remember the hospital because I didn't like the services that they rendered to me, so I didn't even bother to keep the name of the hospital in my head.

Additionally, two women who presented to the TFC for repair surgery had a history of at least one previous fistula repair; in both instances the surgeries were unsuccessful. As a result of unskilled care, one woman with a vesicovaginal fistula further developed a rectal vaginal fistula after a surgeon, likely not adequately trained in fistula repair, attempted to conduct the surgery.

4.7.1.2 "We were told to come back." Whether it was the woman herself, or the family members that accompanied her, all of the participants reported difficulties in accessing treatment for OF. As previously suggested, although distances travelled were not far, the lack of transportation made it very difficult for participants to reach the TFC. Furthermore, women and families experienced extreme "let down" when they reached the centre only to discover that the specialists were not there and they would have to wait. One woman shared her experience of having to wait or continue coming back and forth to the TFC to see if the specialist was around:

> So when I came back to report this is what is happening then they told me that a white doctor again will be coming . . . and I didn't know I was so desperate then. Once and a while I just pass by to come and find out, "oh when is the doctor coming?" Once in a while I pass by when is the doctor coming. They told me, "oh, I should be patient; when the time comes they will call me". (Women with OF)

Waiting at the centre placed further financial constraints on women and their families. Since no meals or supplies were provided for women, family members often had to return to their villages to gather supplies to bring back to Tamale. These unexpected costs of transportation back to their homes and the cost of purchasing food and supplies resulted in significant financial strain for entire families. Women who did not have relatives to assist and could not afford to buy food themselves ended up eating very little and relied only on "good Samaritans" to provide them with food.

4.7.2 Feelings of frustration. Although the TFC has been operating since 2009, support for the centre has been dwindling. According to the director of the TFC, there is currently "practically no management structure for the fistula centre." Staffs who are currently working at the centre are not permanent. Several nurses at the centre are employed by the Central Hospital and posted to the fistula centre. According to the TFC director, nurses working at the centre "virtually have no formal training in fistula [care]." Data generated from informal conversations with staff working at the TFC revealed that several staff not only lacked formal training in regards to caring for clients with fistula or those recovering from fistula repair surgery, they also did not have any formal nurses training. One lady explained that she was not paid to come to the centre nor had she taken any formal nursing or healthcare training. Rather, she noted that she came to the clinic to "keep from boredom."

The majority of women who required the services provided at the TFC were poor and had very few resources to pay for their care and treatment. Because the women at the TFC may have no financial resources, it is very difficult to find staff willing to work at the centre. A local surgeon explains the difficulty in finding staff, particularly surgeons, interested in working with OF clients since financial benefits are minimal:

> Though we have hospitals that the patient can be treated, the condition is such that nobody, no doctor, no gynecologist wants to waste his or her time on it. In the first place, it doesn't give any financial benefit. It rather may be draining that person's fund where there are surgeries that you just have to dish out your own money and then you maybe wasting your time thereabout. (Surgeon)

Moreover, a surgeon described his frustration working at the centre.

> I think I have done enough, but the fact is . . . nobody, many doctors will not even like getting involved in fistula activity because it full of frustration.

4.7.3 Waiting for the "White Doctors." Lack of interest by local surgeons and healthcare practitioners has resulted in many foreign surgeons travelling to the TFC on a volunteer basis to perform surgeries. Consequently, many women and their families have to wait a very unpredictable and often lengthy period of time before they are able to have the repair surgery. One participant who had already had her fistula repair surgery described her experience of waiting at the centre before she was able to have the surgery:

> I had to come and wait at the fistula centre for some time before the white doctor came and did the surgery.

Considering that the women often waited for significant time periods before having their surgeries, many with less than adequate nutrition or support, all of the participants expressed joy when the visiting surgeon finally arrived at the clinic. One family member tells of how he witnessed this arrival:

> When I saw that guy coming and then the white person there too, that was the doctor coming. And they all stood up and then they were clapping hand[s]; those who came there stopped cooking. (Relative)

Another participant's husband reported his wife's hopes with regards to having the fistula repair surgery:

> It is her hope and prayer that God will give this white man . . . the white men who come to do the operation, more wisdom to be able to attend to these women, to help all women in Ghana. It means that if they, they can't, they're in trouble because nobody, no woman can go out, no women can do anything. (Husband)

4.7.4 "That I don't know." Almost all of the women affected by OF and those close to them did not know what caused the fistula to develop. Various reasons were given as to what they believed to be the cause of the condition. Several participants attributed the development of the OF to be the result of interventions performed by skilled persons at a healthcare centre and/or hospital. Others believed the condition developed as a result of ‘evil spirits’ and spells cast by other women in their communities. In other cases, women believed the OF developed as a result of a sin they had committed. For example, one participant explained that she was not sure what had caused her to develop the condition but explained that she thought it may be related to a sin she done in the past.

> I kept thinking that, what have I done? Or what sin have I committed that I’m getting this illness? I don’t know. I don’t know. (Woman with OF)

Not only were women and those close to them unaware of what caused the OF to develop, informal conversations with unskilled and skilled health care providers in the villages revealed that there was also a lack of correct information in determining the causes associated with the condition. For example, when talking with a TBA she explained that she believed it was the result of interventions by ‘knives’ that caused the condition to develop.

4.7.5 I just kept ‘thinking and thinking’. Much of UNFPA’s strategy in addressing the high prevalence of OF found in the North includes, ‘prevention and awareness’ (UNFPA, 2004). The organization has been working in the country since 2003, however almost all of the women and families who arrived at the TFC had never heard of OF before coming to Tamale and were not sure of what caused the ‘condition of leaking urine.’ When participants were asked what they believed caused OF, typically they did not know. One said:

> Well, I don't know what is the cause because I've been thinking and thinking and thinking. I don't know what exactly is the cause of this condition. (Husband)

Not only were women and family members unaware

To further generate awareness, the UNFPA uses land rovers equipped with speakers to travel to communities broadcasting messages about OF awareness and treatment. Again these broadcast messages are in English and considering the majority of women at risk and living with OF may not understand English and/or are illiterate such strategies seem ineffective.

4.8. Self Support and the Support of other Women.

Although the majority of women arrived at the TFC with relatives, several women reported to having no support. In these situations they had to be their own source of support. This courage and determination is highlighted in the following narration:

> I'm a patient here, I'm here because I have a problem with urine leaking and that is who I am, I'm a patient here with urine leaking, nothing more, nothing less and I'm here and I mean business.

4.8.1. "I am not the only one." The majority of women reported that they believed they were the only one with the condition of 'leaking urine.' Women, particularly those who's travelled alone, felt relief upon arriving at the clinic to find other women with the same condition. While waiting at the clinic, women tended to congregate together outside of the TFC, thus acquiring an unexpected and additional source of mutual support. Women at the TFC tended to sit outside the centre with one another for the majority of the day; talking, cooking, and washing. All of these social activities appeared to serve as a source of support for women waiting to have the OF repair surgery. One participant described how his relative felt when they arrived at the TFC:

> She thought she was the only one living with that condition until she came to this centre. (Relative)

One woman described her experience of discovering other women who had the same condition:

> Where we were sitting virtually the whole place was wet and this one turns and sees you are wet she turns and asks you . . . "Oh are you also suffering from the same condition as mine?" And then I had to respond…

Another said:

> So at least I was also sitting there also observing. I observed that other women too were also wet. The I said, Oh . . . then I am not the only one.

4.9 Summary of Findings

In summary, the perceptions of support described by women, and those close to them predominantly focused on information and economic support. Generally, when asked about support, women and those close to them, described support as tangible, mainly the provision of basic needs, such as a place to live, money for food, transportation and treatment at the TFC. While women described this support as helpful many explained that this did not suffice in meeting their needs, particularly their social and emotional needs. Yet there seems to be a sense of community that is created by the women themselves at the TFC and appears to be, in one way or another, providing aspects of emotional and social support. Although, frustrated with the formal support the TFC appears to offer, women at the clinic seem to have formed a social support network for one another.

Chapter 5

Discussion

5.1 Discussion of Results

The purpose of this research was to gain insight into how spouses/partners, family members, friends and relatives describe the support that they provide to women affected by OF. Throughout the research process, themes emerged which reflected knowledge, beliefs and attitudes that influenced the types of support that were provided to women at the TFC. These themes included support from families, spouses and even self and that could be regarded as economic, formal, and informal.

The issue of OF is complex and a proper understanding of that complexity is required to fully address how women and those associated with them perceive support. All women in this study, with the exception of one, sustained their OF as a result of prolonged labour. It is well documented that prolonged labour causing OF results from a multifaceted interplay of biological, social, economic, and political factors (Muleta et al., 2008; Mwini-Nyaledzigbor et al., 2013; Roush, 2009;). Through various channels, these factors combine to create the "obstructed labor injury complex" described by Arrowsmith as a syndrome, characterized by numerous injuries that result in and occur as result of fistula formation (Arrowsmith, Hamlin & Wall, 1996). Poverty, malnutrition, gender, insufficient health services, and lack of education were evident in all accounts provided by study participants.

All of the women who had developed an OF were mature and living in villages near Tamale. In this regard, the non-probability sample in this study differed from those recorded in existing literature profiling OF as a condition that predominantly affects young girls living in rural areas (Engender Health 2004; Roush, 2009; UNFPA, 2004). In studies conducted in Zambia and Ethiopia, it was reported that the median age of women who developed a fistula was 18 years, and 22 years respectively, with the majority of women residing in remote areas (Holme, Breen, & MacArthur, 2007; Muleta et al., 2008). In addition, it was reported in a qualitative study conducted in the North of Ghana, that the predominance of women living with OF resided in rural villages, far away from formal healthcare and medical facilities (Mwini-Nyaledzigbor et al., 2013). However, it must be emphasized that the women living with OF in this study were older, with a modal age of 46. In this regard, the age of women in that sample was similar to the age of participants in the current study.

An encouraging finding from this study is that several partners remained with their wives after they developed OF. Unlike women living with OF in other parts of sub-Saharan Africa, women in this study typically remained married after developing OF (Bangser et al., 2011; Muleta et al., 2008; Pope et al., 2011; Yeakey et al., 2009). Moreover, several women reported that their husbands were their main source of support after developing an OF. However, the type of support they described was largely economic, providing them with money for food, transportation and a place to live. The type of marriage described by women in this study was similar to findings reported in other studies conducted in sub-Saharan Africa, in that they remained married but did not continue any sexual relations with their husbands and in a few instances, lived in a separate house (Mwini-Nyaledzigbor et al., 2013; Muleta et al., 2008; Roush, 2009). It is important to highlight that the majority of women in the current study had only lived with a fistula for a short duration of time, usually less than 24 months. The author postulates that this may have an impact on a husband's decision to stay with his wife despite her development of an OF as perhaps the full extent of the illness had not yet been realized within that timeframe. It is well documented that the longer a women lives with a fistula, the more likely she is to be divorced (Bangser et al., 2011; Roush 2009). Furthermore, it is highlighted in other research that women who have timely access to surgery for OF repair are also significantly less likely to be divorced (Bangser et al., 2011; Roush 2009). In the cultural context, the preservation of marriage is an important factor that determines how much support a woman will receive. Without the support of a husband, the likelihood of a woman continuing a healthy and productive existence is rare. To ensure women and families can be better supported, every attempt must be made to ensure that women have access to timely, quality care and treatment.

The participants described family members as their most reliable form of support, particularly parents. Given the cultural context, where family ties are very strong and nearly ‘unbreakable,’ parents seemed to feel responsible for their daughters. Generally, this type of support was limited to provision of food, shelter, and clothing. Additionally, women described receiving money for transportation to the healthcare centre and/or being accompanied to the TFC for treatment. Parents tended to feel especially responsible in providing these tangible supports if his/her daughter no longer had a husband/partner. However, not unlike spousal/partner support, family support can be withdrawn when it becomes probable that the women’s condition will be chronic (Mwini-Nyaledzigbor et al., 2013; Wall, 2006).

Generally, all participants reported experiencing a loss of support from someone close to them after developing a fistula. Despite having a family member or spouse to support them with economic assistance, most participants reported having very little emotional and social support. An interesting finding, is the sense of relief women felt in finding out other women also had OF. Despite the frustration encountered with the formal care offered at the TFC, women generally spoke of the relief they felt upon arriving at the centre, specifically to find out that there were others with the same condition. At the TFC, it appeared that a social support network had formed between the clients. Women appeared to establish relationships with one another; spending the majority of the day outside of the clinic, cooking, washing and sitting together. This is a significant findings as it appears women living with OF or have had OF in the past may be an important source of support for one another, particularly social and emotional support.

Unlike in other parts of sub-Saharan Africa, where the majority of women suffering from OF tend to be Muslim, the greater number of women and families observed and/or interviewed in this study were Christian. Many women and families described how members of their congregation pooled money so that they would be able to receive treatment. Occasionally, it was priests who travelled with women and their families to the TFC and provided food and money to support them while they received treatment. These findings suggest that particular religious affiliations may contribute to a women's ability to seek timely OF treatment and care.

It is noteworthy that in this study, most of the women who arrived at the TFC had previously presented at a formal healthcare facility for OF treatment. In a few instances, participants had already had one or two unsuccessful surgical OF repairs. The author suggests that this may be a result of the self-selection of women and families who were already aware that OF could be surgically repaired. This could explain why women who arrived at the TFC appeared to be older and have a greater amount of family support than that reported in the literature. It is possible that women with very little support never reached the TFC and were the least likely to have access to treatment and repair. Again, religion could have an influence on a woman's ability to gather the resources needed for information and/or travel. According to a Ghanaian investigator, Christian women tend to be more educated, have fewer numbers of children, live in urban areas and in wealthier households. She also noted that they are less likely to be in polygamous marriages than women of other faiths (Muslim and traditional African religions) so they would be less likely to be rejected or displaced in favour of another spouse (Gyimah, Takyi, & Addai, 2006, p. 2936). Moreover, Christian women are more likely to have the money to travel and are accustomed to travelling alone. In contrast, it may not be acceptable for a Muslim woman to travel to the TFC alone or without the consent of a man (husband, father or father in-law). Nevertheless, these findings reflect the inefficiency and the quality of the services for fistula treatment and support for women in the Northern region of Ghana living with OF.

However important the TFC has been to women suffering from OF, the facility is struggling for various reasons. When first arriving at the TFC, it was apparent that the centre was not functioning as a specialized fistula hospital dedicated only to fistula repair. Although it has been documented that establishing dedicated fistula centres in high prevalence areas is an effective strategy in supporting women living with OF, the TFC appeared to be functioning in a manner similar to a short-term program rather than a hospital committed to fistula repair (Cam et al., 2009). Similar to short-term OF repair programs in Ethiopia, Niger, and Nigeria, the TFC faced significant institutional barriers (Ahmed & Holtz., 2007; Cam et al., 2009; Wall, 2007). Although the centre was developed as a partnership project between Ghana Health Services and the UNFPA, it appears that support for the centre is diminishing. Significant barriers to providing quality care for women at the TFC include shortages of proper surgical and medical supplies, lack of qualified staff working at the centre and scarcity of funding to provide food for women while they await or recover from surgery to repair their fistulas.

In addition to physical barriers, there were also more intangible difficulties in establishing the centre as a high functioning hospital. From the perspectives of the nurse-midwives, nurses, physicians and other staff at the TFC, they did not feel like they received adequate training in regards to caring for clients and families affected by OF. Nurses at the clinic reported that they had not been exposed to information about OF during their nurses training; others reported that they had not actually been trained as a nurse.

There was a degree of tension between women with OF and the staff at the TFC. Lack of communication regarding the schedule for surgeries resulted in women and families experiencing a great deal of frustration. The women would arrive at the clinic only to be told to come back because the volunteer surgeon was “not in.” Nurses at the clinic were often unclear of the timelines for the return of the visiting surgeon and as a result, were often not able to provide guidance to clients about when to arrive for surgery. There also appeared to be tension between the volunteer staff coming to conduct the surgeries and the local staff at the centre, a commonly cited problem encountered by other voluntary fistula repair campaigns (Cam et al., 2009; Wall, 2007). Volunteer staff arrived with the expectation that preoperative care would have been completed. However, local nursing staff was often unaware of these expectations, and as a result surgery planned by volunteer surgeons was further delayed. In some instances, women who were not deemed healthy enough by the volunteer team were turned away.

Although, the UNFPA maintains its stance of continuing support for the 'Global Campaign to End Fistula' it appears that this support is fragmented and inadequate in meeting the needs of women at risk for and living with OF in Northern Ghana (UNFPA, 2004). With respect to OF, the UNFPA established its presence in Ghana in 2003, yet almost all of women and families who arrived at the TFC had never heard of OF before they came and stated that they were not sure what caused the 'condition of leaking urine.' In an attempt to increase awareness, currently the UNFPA provides billboards about OF on the major roads and highways in and around Tamale. These billboards are in English and cost around 300 Ghanaian cedes. Additionally, the UNFPA has land rovers equipped with speakers that travel to communities broadcasting messages about OF awareness and treatment. These broadcast messages are in English so considering that majority of women at risk and living with OF are illiterate and/or do not understand English, these strategies may not prove most effective. These findings highlight the well-documented challenges associated with developmental aid: overlap and duplication of programs, corruption, fragmented services, and lack of harmonization between the aid organization and the local government (Easterly, 2007; Moyo, 2009; Orbinski, 2008). Like fistula campaigns conducted in other parts of sub-Saharan Africa where there is not adequate support, even the best intentions can produce unreliable results.

5.2 Threats to Rigour

Since the investigator was not Ghanaian, her presence as an outsider would shape the research process. The etic rather than emic perspective can be considered a threat to credibility but can also strengthen the research design (Fontaine, 2009). To ameliorate a potential “outsider” effect, the researcher lived and worked closely with her Ghanaian key informant to ensure that cultural considerations were taken into account throughout the research process. The researcher’s obvious physical differences and limited languages skills proved difficult in attempting to “blend” into the setting, although the longer the researcher was present in the setting, the more comfortable insiders appeared to become with her presence. However, she believed that insiders possibly viewed her as someone to impress and might have adjusted their comments accordingly.

There is no risk of challenges to inter rater reliability within this study, as the researcher was the only person collecting data. To reduce the possibility of potential personal biases, the researcher kept an accurate and complete audit trail to document decisions made throughout the research process. Furthermore, the researcher provided her supervisor with all transcript data. Transcripts were reviewed and themes that were identified by the researcher were confirmed as logical and defensible by her supervising professor.

There was a risk of response bias in this study. In several instances, participants appeared to report what they believed the researcher wanted to hear rather than their true perceptions. It was known to the participants that the researcher was interested in what support was available for women experiencing OF. What participants reported as the types of support provided to women and families was not always observed at the TFC or in the communities. Nevertheless, it was the triangulation of data collections methods including non-participant observation, review of records and formal/informal interviews that supported a clearer understanding of the findings.

5.3 Limitations

This study was conducted within a limited timeframe where the researcher was able to spend a total of eight weeks in the country specifically to collect data during the months of October and November 2013. It was during these two months that the volunteer surgical OF missions were scheduled; thus the situation could be very different during other times of the year. The researcher's field experience coincided with the season of harvest in the Northern Region and so she cannot be certain whether or not the season influenced the presence of men at the TFC, since farming is the most predominant occupation for men in the North. However, from informal conversations with insiders, it appeared that men did not frequent the TFC at any time during the course of the year. The researcher had spent twelve weeks in the country in 2010 and during this time she was able to visit and practice as a nursing student in various rural and urban clinical sites. This previous experience and familiarization with the culture and the formal healthcare system assisted in clarifying themes and patterns she witnessed at the TFC.

The researcher was not able to speak in the local language and most insiders spoke in their native tongue. Conversations between staff, patients and families at the TFC were often in the local language. As a result, her ability to fully explore the dynamics of these relationships was limited. To attempt to address this limitation, the researcher would ask nurse-midwives and family members at the TFC to clarify in English. Often, the researcher would ask a key informant to translate the conversations that were taking place; however, the researcher could not be certain of the translation. Despite not being able to speak the local dialects, the researcher's previous experience in the country assisted in displaying cultural etiquette during conversations held between her and participants.

Data were collected primarily at one healthcare centre and in three villages surrounding the capital city of the Northern region. It cannot be assumed that the situation for women and families is the same throughout the entire region or in other regions or other parts of the country. It can be argued that the women who were recruited for this study might have had access to adequate economic resources and, as a result, these findings may not accurately represent the majority of Ghanaian women living with OF. It is possible that perceptions and support would be different in remote and rural communities so it is difficult to transfer findings for use in other areas. However, combined with findings from other studies done across sub-Saharan Africa, this information can be used to formulate a more detailed picture of the OF experience for women in this region and what can be done to address it.

5.4 Implications for Nursing Practice

Findings from this study indicate that greater support is needed for women and families affected by fistula in the Northern Region of Ghana. Caring for women dealing with OF is a specialty area and thus requires specialized training for nurses who provide support for them. Specific and specialized training that meets international standards needs to be provided to staff working at the TFC, without personal cost to them. Such programs can include sensitivity training, protocols and criteria for management of OF. Educational programs that address the provision of holistic care to women with OF and their families can be made available through continuing education to healthcare professionals working in the area to enhance support. Nurse-midwives and public health nurses in the community could include information regarding the risks of developing OF during antenatal clinic visits.

The ability of healthcare providers to provide comprehensive, holistic, and quality care is influenced by available resources, acceptability to the culture, and institutional regulations. Providing such care is difficult in a setting such as the TFC as it limited by a lack of resources and educational opportunities for staff working there. However, simple strategies that require very few resources, such as increased communication between clients and staff, could be implemented to build a greater support network. Examples of such strategies could include nurses and nurse-midwives using therapeutic communication during conversations and interactions with clients and families at the TFC.

5.5 Implications for Education

Findings from this study can provide healthcare professionals and policy makers with a better understanding of the challenges facing women awaiting fistula repair. Furthermore, findings can be used to recommend more effective and culturally safe maternal health interventions by including these perspectives from family members, spouses and others close to women affected by OF. Greater commitment from educators, policy makers and educational administrators is needed to ensure accurate information/policy regarding the causes, prevention, and treatment of OF is taught in all nursing, midwifery and medical schools in Ghana. Emphasis can be placed on increasing the training possibilities for supervised practice to develop entry-to-practice competencies for nurses, midwives, and doctors interested in working in the area, particularly for those practicing in the North. Specialized, specific training organized by the professionals within the Ministry of Health to facilitate the initiation and continuation of training for those caring for women receiving OF repair treatment. Nurses and other informed parties could meet with stakeholders (i.e. representatives from the Ghana Ministry of Health, UNFPA delegates) to discuss specific requests for supervised practice that will assist in meeting such competencies.

It is unlikely that all Ghanaian women requiring OF repair surgery will receive it; therefore, local public health workers and community nurses who work with these women could examine innovative ways to address both the physical and social problems associated with the condition. For example, nurses in the community could develop a 'Caring for Women with Fistula' module. This module could include information focused on teaching women how to prevent skin breakdown, decrease risks of infection and inexpensive strategies to keep dry and clean.

5.6 Implications for Research

Further research is required to explore the impact OF has on spouses/partners and family members in other regions of the country, particularly in rural and remote areas. Findings from this study were limited to one clinic in the metropolis of Tamale and surrounding communities; as a result, experiences of women and families in other more remote or depressed areas of the country may be different. Capturing experiences from a wide variety of women and families will be useful in determining how support is defined and what kind of support would be most acceptable and effective for families affected by OF. Further research may be helpful in determining if there are any identifiable defining characteristics of men who were supportive decided to stay with their wives. This knowledge can be used to identify what types of support can be offered to couples in order to preserve more marriages.

As previously mentioned, women who arrived at the TFC appeared to have a greater amount of family support than was suggested by findings from previous research conducted in Ghana and other parts of sub-Saharan Africa. The researcher postulates that this could be the result of significant cultural and social factors such as religion, gender, income, and occupation. The researcher further hypothesizes that religion may be an important factor in understanding the support for women with OF; research exploring religious belief systems and affiliation may provide more insight into OF service utilization in Ghana. It is further recommended that interprofessional participatory action research to investigate traditional beliefs surrounding OF would enhance knowledge of the perceptions of common beliefs about what causes this problem and how to prevent it. Understanding the values and beliefs as well as acceptable behaviours among traditional cultural will provide more information on how to address misconceptions that result in stigmatizing women with OF and possibly their families. This will further assist in preventing the condition from occurring or minimizing its morbidity.

To enhance what is known with respect to the prevalence OF in Ghana, quantifiable and verifiable data on the number and extent of OF surgical repair cases being conducted in the country needs to be collected. This lack of evidence makes it extremely difficult to combat the situation. Without such information, policy makers, public health directors and healthcare professionals have difficulty planning for OF treatment services.

Lastly, with the establishment of the TFC there is now as small cadre of women who have had their OF repaired. Although fortunate to have undergone the surgery, the majority of these women have been sent away without little support or follow-up. This highlights a missed opportunity to fully understand the reintegration process these women experience upon returning to their communities. Exploratory research investigating this process can provide invaluable knowledge on the factors that facilitate or hinder reintegration.

5.7 Implications for Policy

To better address the significance of OF in Ghana, greater commitment from policy makers is required. Support for women and families affected by OF could be significantly improved if the condition was regarded as a public health issue. Ghanaian investigators, Prudence Mwini-Nyaledzigbor and Alice Agana, who have expertise in this area could be supported by their institutions to submit their findings to the Ghanaian Ministry of Health with a request to consider re-evaluating the current delivery of reproductive and maternal healthcare services being provided in the country. An emphasis on reallocation of funds towards scaling up Emergency Obstetrical Care is essential in preventing the occurrence of OF and failing that the detrimental health and wellbeing outcomes. Ensuring appropriate training of all OF providers, criterion-based audits, and availability of needed medical supplies, are possible pathways to evaluate and ensure the quality of such services.

In order for meaningful OF treatment and compassionate care to occur, the creation of appropriate policies is required. Standards, algorithms and protocols outlining the management of OF could be established through inter professional collaboration in conjunction with healthcare professionals already practicing in the field. Education and training focused on these guidelines could then be made available, without cost, for healthcare practitioners working with women and families affected by OF.

Lastly, aid organizations, local and foreign healthcare professionals, community members and educators could focus on working more collaboratively with the government of Ghana. If the government was able to work with these stakeholders, it may be possible to improve the effectiveness of the treatment services provided to women affected by OF in Northern Ghana.

5.8 Recommendations

Findings from this study extend knowledge about the phenomena of OF in the context of Northern Ghana. By including the voices of women, spouses/partners, family members, relatives, healthcare professionals and community members, this study can contribute to limited evidence surrounding the types of support perceived by women affected by OF. Based on these findings, several recommendations can be made:

(i) The Tamale Fistula Centre be supported to uphold its mandate as a dedicated OF treatment centre. New and existing staff be trained and adequately supervised so that they can provide quality OF repair treatment and care according to guidelines and competencies consistent with global health standards. The Ghanaian government and the UNFPA collaborate to ensure the facility is supplied with basic resources to carry out surgery and compensate all levels of providers and other staff members who practice at the clinic. To prevent further complications and ensure optimum recovery, women undergoing surgery a strategy to ensure that adequate nutritional requirements are met prior to and after surgery. This may require re-evaluating the cost of a course of care and budgeting for adequate resources. Funding for the centre needs to be allocated to ensure a dedicated fistula specialist is available at all times. This will require a significant increase in funding; however, in the interim, there needs to be clarity with respect to predictable times when a fistula specialist is available e.g. every second month for three to four weeks. That way nurses at the TFC can provide women and families with an accurate time frame as to when they can expect to receive treatment.

(ii) Facilitate collaboration between the UNFPA and Ghana Health Services to harmonize efforts to improve the quality of care for women receiving OF treatment surgery. For women and families at the TFC, care could be improved if the centre received adequate support from the Ghanaian Ministry of Health and the UNFPA. Currently the two groups appear to be non-aligned with one another. For example, the UNFPA offers skills training workshops for women who have had a fistula repair surgery. Ideally, the UNFPA could coordinate with the TFC in terms of bringing clients back to Tamale for the training. There the providers at the fistula centre could complete the follow-up care from surgery, thus saving women and families the difficult and expensive trip back to Tamale.

(iii) Strategies and interventions should be implemented to heighten awareness of OF and its causes. A more feasible strategy than broadcast UNFPA messages in English would be to directly raise awareness through front line workers including public health nurses, community health workers, and TBA's about the risks and warning signs of pregnancy-related complications. In addition, public health nurses and midwives through in-service training can educate young women about the risks of developing OF during antenatal care, possibly through modules developed around complications and potential dangers during labour. Public service announcements could be translated into local languages and broadcasted via radio as most people in villages have access to radios and cell phones. Furthermore, health education units could design posters using pictures and these could be displayed in regional hospitals, maternity care homes, CHPS compounds and other community structures (markets, schools, churches, mosques).

(iv) Nurses, and nurse-midwives working at the TFC need to be provided with specialty training. The Hamlin Fistula Hospital in Ethiopia is an example of a institution that provides comprehensive holistic training for healthcare professionals working in the area of OF. The TFC could establish training programs modeled on this approach, whereby nurses receive training on therapeutic counseling to help women cope with the challenges associated with OF (Hamlin & Nicholson, 1996). Moreover, nurses and staff at the TFC could work with the UNFPA to establish support groups for women and family members who come to the centre. Separate support groups could be created based on the needs of members, i.e., women awaiting fistula repair surgery, husbands/partners of women living with OF, women who have had OF repair, and children/relatives of women with OF. All of these groups could serve as support networks for people affected by the condition and build on the existing inclination that Ghanaians have to form supportive communities and the informal supportive relationships among affected women at the TFC was obvious. Finally, nurses and staff working at the centre be provided an opportunity to be familiar with the resources available for women and families so they can make appropriate referrals. This could include agencies and programs such as the skills training workshop conducted by the UNFPA and funding agencies offering economic resources for women and families in need. Considering the landscape of NGO's and aid organizations operating in Tamale, there needs to be a push for utilizing this assistance to ensure women have access to having their basic needs met, particularly with respect to nutrition so that care and treatment can be maximized.

(v) Access to healthcare facilities and fistula treatment centres should be facilitated for OF patients and families. Transportation is a significant barrier in terms of preventing women from receiving OF treatment repair and follow-up care. The government could consider allocating resources to facilitate improving the infrastructure and road networks in the North. Affordable and reliable means of transport will not only improve access for women who wish to have OF repair surgery, it will further prevent OF from occurring in the first place as women will have easier access to formal healthcare. Transportation needs to be made more affordable, particularly when women are in labour and in need of transport to a healthcare facility. For example, hospitals and maternity care clinics could negotiate with the numerous NGO's with offices in the area to budget for reimbursement to taxi drivers or other drivers that transport laboring women or women in need of maternity care. Further, the UNFPA campaigns could include travel vouchers for women with OF needing to travel to the TFC.

5.9 Conclusion

Obstetric fistula can no longer remain a neglected global health issue. This condition rarely occurs in higher income countries and effective treatment has been available in North America and Europe for almost a century; however, OF continues to occur not only in Ghana but also throughout many other sub-Saharan African countries. The purpose of the study was to gain insight about the types of informal support women living with OF perceive from those closest to them. Findings from this study highlight that although women perceive informal support from spouses/partner, family members and other relatives, much of this support is limited to providing for their basic needs. Through this study, women, husbands, fathers and mothers were able to describe, in their own voices, the challenges they faced due to their own condition or the condition of their loved one. This preventable and treatable condition has caused the loss of self-esteem, roles, livelihood and economic self-sufficiency for many women and families. It has also resulted in traumatic experiences for patients and families at formal healthcare facilities, causing vivid physical and psychosocial pain. By conducting this study and giving women and families a voice, these findings will hopefully emphasize the call for action aimed at preventing and treating this debilitating condition.

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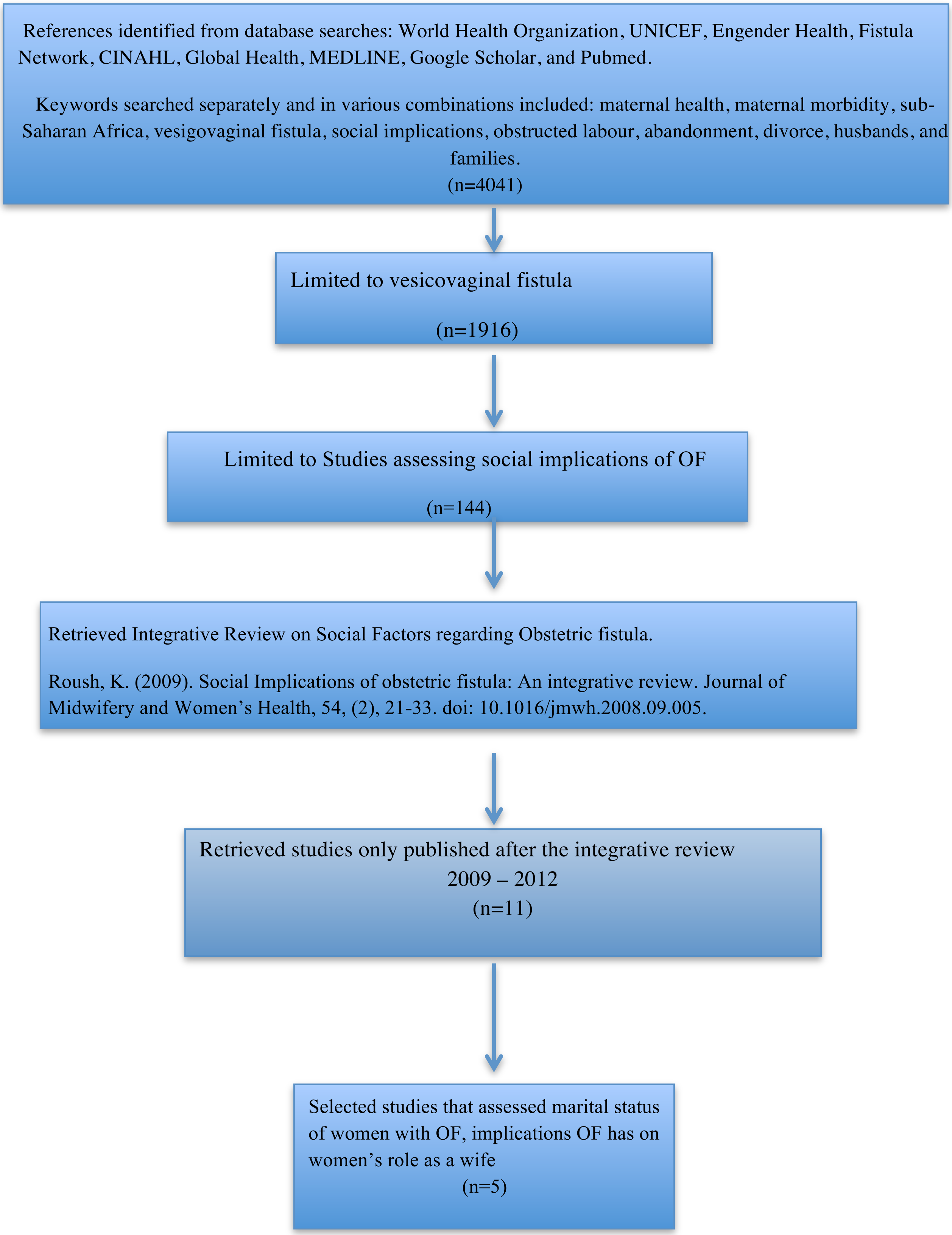
Appendices

Appendix A – Literature Review Search Strategies

Search Strategies



References identified from database searches: World Health Organization, UNICEF, Engender Health, Fistula Network, CINAHL, Global Health, MEDLINE, Google Scholar, and Pubmed.

Keywords searched separately and in various combinations included: maternal health, maternal morbidity, sub-Saharan Africa, vesigovaginal fistula, social implications, obstructed labour, abandonment, divorce, husbands, and families.
(n=4041)

Limited to vesicovaginal fistula

(n=1916)

Limited to Studies assessing social implications of OF

(n=144)

Retrieved Integrative Review on Social Factors regarding Obstetric fistula.

Roush, K. (2009). Social Implications of obstetric fistula: An integrative review. Journal of Midwifery and Women's Health, 54, (2), 21-33. doi: 10.1016/jmwh.2008.09.005.

Retrieved studies only published after the integrative review
2009 – 2012
(n=11)

Selected studies that assessed marital status of women with OF, implications OF has on women's role as a wife
(n=5)

Appendix B – Table of the Studies Included in the Literature Review

Study	Setting	Design	Sample	Methods	Findings
Ahmed, S., Holtz, S.A. (2007).	Not applicable	Meta analysis of 8 studies conducted in sub-Saharan Africa	8 studies	Meta-analysis	An average of 85% of women who have suffered from OF experience fetal death in labour.
Cam et al., 2010.	Niger, at a regional hospital	Non-experimental Evaluation study	62 women	Evaluated a volunteer fistula campaign carried out in a regional hospital in Niger	Significant problems were encountered by the volunteers who tried to carry out the campaign, including lack of screening and women's health status prior to surgery, inability for follow up. Conclusions: Effort should be directed at establishing specialist centres in countries with a high burden, with full time skilled professionals.
Mselle et al., 2011.	Bungando Medical Clinic, Dar es Salaam, Tanzania, conducted between Oct. 2008 to Feb. 2012.	Cross-sectional mixed method, non experimental, descriptive. Sequential exploratory mixed method design.	Convenience samples: 16 affected women interviewed 151 affected women responded to the questionnaire 12 affected women and 6	Quantitative methods: closed ended questionnaire. Qualitative methods: Semi structured interviews & Focus group discussion (FGD) Two FGD's: One with only affected women and one with affected	Significant association between living alone and duration women had the fistula (P=0.0111), the longer women had the fistula the more likely they were to live alone. 82% of affected

			of their husbands participated in a focus group discussion.	women and their husbands.	women were still married during the study period and among 70% of them had suffered from OF for less than a year. 39% of affected women were divorced.
Muleta et al., 2008.	Ethiopia Study was conducted in 7 administrative regions of the country between January and June 2005	Cross-sectional Mixed methods Design Quantitative portion: Cross-sectional analytic study	Five stage sampling procedure was used in the 7 selected regions of the country. In each administrative region a lower level administration (districts, villages) were randomly selected. All households in these lower level units were visited to identity women who previously or currently had OF. However the actual number of women included was higher. Purposive sample; 52 women	Quantitative Data: Conducted household surveys to collect information on the prevalence of OF, treated and untreated in the regions. Structured Interviews using two different questionnaires. One prepared for women with treated OF and one for women with untreated OF. Qualitative data: In-depth interviews with guiding questions on the development of fistula and its consequences. Interviews were audiotaped with consent of participants. Records were transcribed, translated, coded, and analysis was conducted.	Women with untreated fistula (n=23) 16 women were married; 21 were divorced; and 2 were widowed 37 women lived in the same house as their family; 2 did not, 34 women ate with their family members; 5 did not 23 considered themselves as members of the community; Treated women (n=13); 5 women remained married before having treatment Suicidal ideation reported by six of the untreated women before surgery Combined Characteristics (n=55)

			with OF; 39 treated; 13 untreated.		All the women reported labour of 24 hours or longer, duration ranged from 24 hours to 10 days
Mutambara et al., 2013	Two main hospitals in Zimbabwe	Phenomenological design	4 women with OF	Unstructured interviews	Found that women with Of faced the psychological challenges of helplessness, sadness, suicidal thoughts, stigma, blames, fear, shame and social withdrawal.
Neilson et al., 2009.	Fistula Clinic at Gimbie Adventist Hospital, in West Wollega Zone, Western Ethiopia. Study was conducted between Dec. 2004 to July 2006	Non-experimental Follow-Up Study Comparative Study, utilizing standardized questionnaires	Total of 44 women had been treated at the centre. Out of the 44, 38 women met the eligibility criteria. Out of the 38, all but one women participated	Community-based structured interviews, 14-28 months following fistula repair, using a customized questionnaire addressing urinary health, reproductive health and quality of life	Social and Psychological characteristics: At follow up (mean time for follow up 21 months (range 14-28 months) Surgery improved QofL (measured by modified version of the King's Health Questionnaire) to a significant level (P=0.001) to that experienced before fistula development. Women who had fistula at follow up reported no improvement in QofL compared to time before

					surgery (P=0.1). *Marital Status and Reproductive Health* -5% were divorced while suffering from a fistula At follow up 71% women remained married.
Pope et al., 2011	Bugando Ukerewe, Tanzania Conducted in April and May, 2007	mixed methods Design Comparative study	Purposive sampling and snowball technique were used to select the sample of 71 women. Three groups of women were interviewed (1) Affected women who had received surgical treatment and returned to their communities (n=25) (2) Non-affected women matched by age and socioeconomic circumstance to women in group 1	Mixture of quantitative and qualitative methods were used to explore the social and physical factors influencing a women's ability to reintegrate post repair, and compare the quality of life of affected and non-affected women living in the same communities *Qualitative methods:* Semi-structured interviews with a social mapping exercise *Quantitative methods:* PQoL tool was adapted to context; tool measures an individual's perception of her quality of life. RNLI is an index that measures return or reintegration to normal living, again tool adapted and	Women in group 1 (affected) experience high rate of divorce (56 %) All divorces occurred after getting the fistula, compared to unaffected women in-group 2 (4.3%), 88% of unaffected women was married. One-way ANOVA to compare groups. Average PQoL scores were statistically significantly higher for group 2 compared to group 1 (P=0.001), indicating that on average women who had never suffered from a fistula report higher levels of

			(n=25) (3) Affected women waiting surgery or discharge	piloted in setting.	PQoL compared to women who have had fistula's repaired. significant qualt.finding**** Found women experienced less ostracism including fewer instances of divorce when women's fistulas are repaired soon after development.
Yeakley et al., 2009	Malawi; women living in the Mangochi District of Malawi 45 women with OF 30 Family members	Qualitative, Phenomenological	Purposive 45 affected women; 30 family members	Qualitative; phenomenological approach Unstructured in depth interviews (open ended questions) with women and family members	Themes: OF affects on societal roles; marriage; intimate relationships and childbearing Significant, because of the context (society) Yao community social construction of gender and the role and value of women in society Divorce was common (the majority divorced subjects identified acquiring an OF as the primary cause; decision for divorce was decided by the husband; result:

					abandonment and isolation. Significant finding-A handful of the divorced women were able to remarry and their new husbands were fully aware of the extent of their condition 27% of affected women remained with their husband after acquiring an OF. Polygamy is common in the Yao culture many times the husbands who remained with the wives had other wives or took on another wife.

Appendix C- Quality Appraisal of the Studies Included in the Literature Review

Study	Critical Appraisal Tool Used	Score	Comments
Ahmed, S., Holtz, S.A. (2007).	NA	NA	
Cam et al., 2010.	EPHPP	Moderate	Small sample size, did not indicate withdrawals or drop outs of participants, failed to mention ethical considerations i.e. study reviewed by a local research ethics review board in Niger. Data was collected at only one time and perhaps collecting longitudinal data could strengthen the design.
Mselle, et al., 2011	MMAT	Qualitative: ¾=75% Quantitative: ¼=25% Overall Score-Mixed Methods= 25%	Out of all the quantitative studies, had the largest sample size and explained the calculations for determining adequate sample size. Only study which included men (husbands). Failed to explain or give details regarding the questionnaire used. Failed to make explicit the qualitative methodology utilized.
Muleta et al., 2008	MMAT	Qualitative: ¼ = 25% Quantitative: 2/4 =50% Overall Score: Mixed Methods = 25%	First study to determine the prevalence of the issue at a national level (Ethiopia). Measurements were clearly defined and data collection methods were made explicit. Shortcomings included failure to explicitly define qualitative methodology and potential biases.
Mutambara et al., 2013			
Nielsen et al., 2009.	MINORS	Adapted scoring out of 14	Failed to clearly define measures. State the study is a follow-up study and provide baseline data of 44 women but do not explain where they got this information from, was there an

		Score = 4 out of 14	initial study? Small sample size limits generalizability and power of statistical analysis (n=44) Fail to mention potential for recall bias as the participants were completing the questionnaires 14-28 months after having had the fistula repair surgery. *** Very difficult to conclude any significance given the issues with design** Ideally a time series design would have been more appropriate, but the authors do acknowledge the difficult in such a study. Overall quality rating is low.
Pope et al., 2011	MMAT	Qualitative: ¾ = 75% Quantitative: 2/4 = 50% Overall Score for Mixed Methods: 50%	Embedded mixed method design was effective in providing a more comprehensive understanding of the re-integration process. Quantitative results complimented qualitative findings. Again, statistical significance is marginal based on the small sample size. Researchers highlight areas for future inquiry.
Yeakley et al., 2009.	CASP Qualitative Assessment Tool	Not applicable	Concerns with stated methodology. States it is a phenomenological study but the method described does not follow either of the conventional phenomenological designs. Issues also with the data collection time frame. Did not explain how findings were influenced by researcher.

Appendix D- Research Setting: Tamale, Ghana

Tamale Demographics

Government:

- Conventional Name: Republic of Ghana (CIA, 2012)
- Constitutional democracy (CIA, 2012)
- Independence from the British: March 1957 (CIA, 2012)

Demographics

- Population estimated in (2012) to be 24.5 million people with a 2.2 % growth rate (CIA, 2012)
- Official Religion: Christian (68.8%) (CIA, 2012)
- Official Language: English. 200 unofficial languages and dialects spoken throughout the country (CIA, 2012)
- Maternal mortality rate (2010): 350 death/100,000 live births (CIA, 2012)
- Infant mortality rate (2012): 40.9 deaths/1000 live births (CIA, 2012)

Geography

- Western Africa, bordering the Gulf of Guinea, between Cote d'Ivoire and Togo (CIA, 2012)
- Capital: Accra (CIA, 2012)
- Ten administrative regions; Ashanti, Brong-Ahafo, Central, Eastern, Greater Accra, Northern, Upper East, Upper West, Volta, Western (CIA, 2012)

Economics

- GDP was worth 39.20 billion U.S dollars in 2012 (World Bank , 2012)
- The highest GDP per capita in Africa at 402.26 dollars in 2012 (CIA, 2012)
- Serve sector accounts for 50% of GDP- gold, cocoa production and oil production since 2010 (World Bank , 2012)
- Health Expenditures: 10.6% of GDP (CIA, 2012)

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Appendix E – Focused Interview Guiding Questions

1. Tell me about yourself?
2. Tell me about your family life?
3. How would your describe your relationship with your partner?
4. What is like to have a wife/partner with OF?
5. How did you feel when you found out your wife/partner got an OF?
6. How did this impact your relationship with one another?
7. What caused the OF?
8. How does this condition affect your family?

Appendix F - Information Letter

Information Letter

Title of Study: Informal Support for women experiencing Obstetric Fistula at the Tamale Fistula Treatment Centre: A Focused Ethnography

Principal Investigator:

Ginger Sullivan, RN, BScN
11118 83 Avenue, Edmonton, Alberta, Canada
T6G 0V1
Phone: Ghana mobile number
E-mail: gsulliva@ualberta.ca

Research/Study Coordinator:
Beverley O'Brien, RN, RM, PhD, Professor
University of Alberta, Faculty of Nursing
780.492.8232., 780.492.2551.
Beverley.obrien@ualberta.ca

Mentor:
Priscilla Naa Boyke
Tamale, Ghana
Phone:0209028948

General Information about Research

If you decide to take part in this study, you will meet with me Ginger Sullivan. I will ask you about the best way that nurses and people in the community can look after women who have an obstetric fistula. I will also ask you what is like to have a wife or a family member with an obstetrical fistula. The talk will not last for more than 1 hour. What you say will be recorded so that I can remember everything you say. No one else will know what you say or even if you decided to be in the study. You can decide where the talk will take place. If you want to speak in your own language, someone who can speak both English and your language will tell me what you are saying. That person will have to promise that they will not tell anyone what you say.

Possible Risks and Discomforts

No harm should come to you if you decide to talk to me. It may cause some people to remember a sad or difficult time. If this happens and you want to talk about it, I will get someone that you choose such as the nurse or your minister to help you feel better. If you decide that you do not want to say anything more, just tell me.

Possible Benefits

This study gives you a chance to talk about what happened and why you think your wife/partner/family member had such a hard time giving birth. You can also tell us what kind of help you think she should have. Many women have obstetric fistula so what you know may help other families in the same situation.

Confidentiality

No one will know that you are in the study unless you want to tell him or her. No one will know what you say to me. Your name will not be put on anything that you tell me. I will write a report to tell people in the Northern Region what I learned by talking to the families of women with a fistula. I will also write a report to tell nurses and others who look after women with obstetric fistula what I learned. This report might be put in a health magazine (journal). If this happens, I will only say that I talked to husbands, family members or others in a community where there was a woman with obstetric fistula. I will not use anyone’s name or the name of the community. What you say could be used in a future study. That will only happen if the researcher gets special permission. After the study is done we still need to store what you say. The information will be securely stored at the University of Alberta, Canada for at least 5 years after the study is over.

I appreciate the time that you give me to help me understand the problem of obstetric fistula. I will give you a small gift as a way of saying thank you. This will be hygiene products (one bar of key soap, and one 250ml bottle of dettol).

Voluntary Participation and Right to Leave the Research

Being in this study is your choice. You do not have to answer any questions that you don’t want to answer. If you decide to be in the study, you can stop talking to me at any time. No one will know if you decide to quit. You just have to tell the researcher that this is what you want to do.

Contacts for Additional Information

If you have any questions about the research now or later, please contact

Ginger Sullivan
780.218.9023, University of Alberta,
Faculty of Nursing, T6G 1C9,
gsulliva@ualberta.ca

Priscilla Naa Boakye
0209028948
Tamale, Ghana
naaboakye76@gmail.com

Or their supervisors:

Prudence Mwini-Nyaledzigbor (Mwinituo), RN, PhD Nursing,
University of Ghana, School of Nursing, Legon,
026-2578-527, mwinituo@yahoo.com,
(Committee member and onsite supervisor)

Beverley O'Brien, RN, RM, PhD, Professor
University of Alberta, Faculty of Nursing
780.492.8232
Beverley.obrien@ualberta.ca
(Supervisor)

Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of Navrongo Health Research Centre (NHRC) and the University of Alberta Health Ethics Review Board. If you have any questions about your rights as a research participant you can contact the IRB Office at the Navrongo Health Research Centre by email at **irb@navrongo-hrc.org** or by telephone at: (233) 03821 22348/22310 or Dr. Koku Awoonor-Williams, Regional Health Directorate, Ghana Health Services, Upper East Region, Bolgatanga. Telephone: (+233) 3820 22335 or at 024 4564120

Appendix G

Consent Form – University of Alberta

Title of Project: Sources of Informal Support for women experiencing Obstetric Fistula: A Focused Ethnography

Principal Investigator(s):
Ginger Sullivan
Phone Number in Ghana:
Email: gsulliva@ualberta.ca

Co-Investigator:
Beverley O'Brien, RN, RM, PhD
University of Alberta, Faculty of Nursing
Phone Number: 780.492.8232
Email: Beverley.obrien@ualberta.ca
(Supervisor)

Prudence Mwini-Nyaledzigbor (Mwinituo), RN, PhD
University of Ghana, School of Nursing, Legon,
Phone Number: 026-2578-527
mwinituo@yahoo.com,

Mentor:
Priscilla Naa Boakye, RN
Tamale, Ghana
Phone Number: 0209028948
naaboakye76@gmail.com

Do you understand that you have been asked to be in a research study?

Yes	No
☐	☐

Have you read and been given a copy of the sheet that tells you about this research study?

Yes	No
☐	☐

Do you understand the benefits and risk involved in taking part in this research?

Yes No

☐ ☐

Have you had the opportunity to ask questions and discuss this study?

Yes No

☐ ☐

Do you understand that you can stop talking to me at anytime and you do not have to tell me or anyone else why?

Yes No

☐ ☐

Has it been explained to you that no one will know you are in the study and no one will know what you tell the researcher (confidentiality)?

Yes No

☐ ☐

Do you understand how the researcher will use this information that she learns?

Yes No

☐ ☐

Do you understand that after the study is done the information (records of the research) will be kept for at least 5 years in a locked cabinet at the University of Alberta, in Canada?

Yes No

☐ ☐

I understand that what I say could be used in future studies only if the researcher gets special permission?

Yes No

☐ ☐

This study was explained to me by: ____

I, ____agree to take part in this study

Signature of research participant: ____

Printed name: ____

Date: _________________

I believe that the person signing this form understand what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee: ____

Date: _________________

THIS INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY IS TO BE GIVEN TO THE RESEARCH PARTICIPANT.

Appendix H - Navrongo Consent Form

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE OF RESEARCH STUDY: Sources of Support for Women Experiencing Obstetrical Fistula (OF) at the Fistula Treatment Centre, Tamale Ghana: A Focused Ethnography
Category of participants

Introduction/Purpose of Study

Sometimes when it is nearly time to give birth, women will have a very slow and painful labour. These pains may last for a long time, even several days. If women are in labour for too long they may develop a serious injury to their birth canal. It is called obstetric fistula. Many women who have an obstetric fistula will leak urine or feces or both until they are able to get treatment. I am a nurse who wants to learn more about how to help women who have this condition. My way of learning is to do a research study. To do this, I want to learn what husbands/partners, other family members and friends of a woman with obstetric fistula think about it and how they are affected. The reason for doing this research study is to find out if there are cultural beliefs about obstetric fistula and the support given to affected women.

Study Procedure

If you decide to take part in this study, you will meet with me Ginger Sullivan. I will ask you about the best way that nurses and people in the community can look after women who have an obstetric fistula. I will also ask you what is like to have a wife or a family member with an obstetrical fistula. The talk will not last for more than 1 hour. What you say will be recorded so that I can remember everything you say. No one else will know what you say or even if you decided to be in the study. You can decide where the talk will take place. If you want to speak in your own language, someone who can speak both English and your language will tell me what you are saying. That person will have to promise that they will not tell anyone what you say.

Benefits/Risks of the Study

No harm should come to you if you decide to talk to me. It may cause some people to remember a sad or difficult time. If this happens and you want to talk about it, I will get someone that you choose such as the nurse or your minister to help you feel better. If you decide that you do not want to say anything more, just tell me.

This study gives you a chance to talk about what happened and why you think your wife/partner/family member had such a hard time giving birth. You can also tell us what kind of help you think she should have. Many women have obstetric fistula so what you know may help other families in the same situation.

Confidentiality

No one will know that you are in the study unless you want to tell him or her. No one will know what you say to me. Your name will not be put on anything that you tell me. I will write a report to tell people in the Northern Region what I learned by talking to the families of women with a fistula. I will also write a report to tell nurses and others who look after women with obstetric fistula what I learned. This report might be put in a health magazine (journal). If this happens, I will only say that I talked to husbands, family members or others in a community where there was a woman with obstetric fistula. I will not use anyone's name or the name of the community. What you say could be used in a future study. That will only happen if the researcher gets special permission. After the study is done we still need to store what you say. The information will be securely stored at the University of Alberta, Canada for at least 5 years after the study is over.

I appreciate the time that you give me to help me understand the problem of obstetric fistula. I will give you a small gift as a way of saying thank you. This will be hygiene products (one bar of key soap, and one 250mls bottle of Dettol).

Withdrawal from study

Being in this study is your choice. You do not have to answer any questions that you don't want to answer. If you decide to be in the study, you can stop talking to me at any time. No one will know if you decide to quit. You just have to tell the researcher that this is what you want to do.

Questions

If you have any questions about the research now or later, please contact
Ginger Sullivan 780.218.9023, University of Alberta, Faculty of Nursing, T6G 1C9, gsulliva@ualberta.ca
Priscilla Naa Boakye 0209028948
Or their supervisors: Prudence Mwini-Nyaledzigbor (Mwinituo), RN, PhD Nursing, University of Ghana, School of Nursing, Legon, 026-2578-527, mwinituo@yahoo.com, (Committee member and onsite supervisor)
Beverley O'Brien, RN, RM, PhD, Professor, University of Alberta, Faculty of Nursing, 780.492.8232., 780.492.2551., Beverley.obrien@ualberta.ca

This research has been reviewed and approved by the Institutional Review Board of Navrongo Health Research Centre and the University of Alberta Health Ethics Review Board. If you have any questions about your rights as a research participant you can contact the IRB Office at the

Navrongo Health Research Centre by email at **irb@navrongo-hrc.org** or by telephone at: (233) 03821 22348/22310 or Dr. Koku Awoonor-Williams, Regional Health Directorate, Ghana Health Services, Upper East Region, Bolgatanga. Telephone: (+233) 3820 22335 or at 024 4564120