EXPERIENCES OF WOMEN LIVING WITH OBSTETRIC FISTULA IN THE MFANTSEMAN MUNICIPALITY OF GHANA

BY

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THIS DISSERTATION IS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON, IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE AWARD OF MASTER OF PUBLIC HEALTH DEGREE

JULY, 2017
DECLARATION

I, Rose Mantey, hereby declare that, except for references to other authors’ work, which I have duly acknowledged herein, this work was done by me under supervision. I further declare that it has been submitted neither in whole nor in part for any degree elsewhere or in this university.

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ROSE MANTEY DR AGNES M. KOTOH
(STUDENT) (SUPERVISOR)

................................................. .................................................
DATE DATE
DEDICATION

I dedicate this work to the Almighty God who has given me the strength, knowledge and wisdom to complete this work. Also, to the less privileged women living with Obstetric Fistula.
ACKNOWLEDGEMENT

I sincerely wish to acknowledge a number of people for their kindness and support throughout this study.

I am indeed grateful to the Almighty God for the strength and support he has given me throughout this program.

My deepest appreciation goes to my supervisor Dr Agnes Millicent Kotoh for her guidance, patience, support and inputs in writing this thesis. I am very grateful for your time coupled with your sense of direction.

I am equally indebted to Dr Wynette Redington, Dr Gabriel Ganyaglo of Korlebu Teaching Hospital and Dr Catherine Husa who supported me in my academic endeavours.

To the Dean, School of Public Health, Professor Richard Adanu, to the Head of Department, Professor Kwesi Torpey, and to all faculty and staff at the Department of Population, Family and Reproductive Health, many thanks and best wishes of God’s blessings.
ABSTRACT

Background: Obstetric Fistula is an abnormal opening between a woman’s vagina and bladder (Vesico Vagina Fistula (VVF)) and or rectum (Recto Vagina Fistula (RVF)) through which her urine and or faeces continually leaks. This condition often leads to psychosocial, economic or medical care challenges and a potential threat to quality of life.

Objective: The aim of the study was to explore the experiences of women living with Obstetric Fistula at the Mfantseman Municipal Area (MMA).

Methods: This was an exploratory cross-sectional study using qualitative method. Purposive and snowball sampling methods were employed in recruiting participants in the study. Data were collected using in-depth interviews. Thirty-two (32) females living with fistula in the MMA were interviewed. The qualitative data were analysed using thematic content analysis.

Results: Stigmatization, including internal, external and caregiver bias were some of the major challenges encountered by women living with fistula leading to isolation and suicidal tendencies. Women felt either shameful or abnormal because of the leaking and accompanying odour. Interpersonal experiences of stigma occurred such as separation from partners and confrontations with family and community members. Family members of the women were also stigmatized. Many of the women living with fistula developed both positive and negative coping strategies including problem solving (using any available materials to absorb urine or withdrawing from others) and emotional responses (self-encouragement or restlessness and self-worrying).
Conclusion: The study established that women living with fistula in the study area are vulnerable to stigma and some live a life of isolation. However, some develop ways of coping with their condition.

Keywords: Obstetric Fistula, experience, coping strategies.
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<td>CR</td>
<td>Central Region</td>
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<tr>
<td>DHMT</td>
<td>District Health Management Team</td>
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<tr>
<td>GHS</td>
<td>Ghana Health Service</td>
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<tr>
<td>GIS</td>
<td>Geographical Information System</td>
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<td>GSS</td>
<td>Ghana Statistical Service</td>
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<td>IDI</td>
<td>In-depth interview</td>
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<td>MMA</td>
<td>Mfantseman Municipal Area</td>
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<td>OBF</td>
<td>Obstetric fistula</td>
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<tr>
<td>PFRH</td>
<td>Population Family and Reproductive Health</td>
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<tr>
<td>RVF</td>
<td>Recto Vagina Fistula</td>
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<tr>
<td>UNFPA</td>
<td>United Nations Population Fund</td>
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<td>USAID</td>
<td>United States Agency for International Development</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<td>WIFA</td>
<td>Women in fertile Age</td>
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**OPERATIONAL DEFINITION OF TERMS**

**Obstetric:** Anything pertaining to pregnancy, labour and delivery

**Fistula:** An opening between two organs

**Woman:** Females of reproductive age and above (15 years and above)

**Obstetric Fistula:** An abnormal opening between a woman’s vagina and bladder or between the vagina and rectum.

**Vesico Vagina Fistula:** An abnormal opening between a woman’s vagina and bladder.

**Recto Vagina Fistula:** An abnormal opening between a woman’s vagina and rectum.

**Women living with fistula:** A woman who has developed an opening between her vagina and the bladder or between her vagina and the rectum.

**Coping strategy:** Any measures employed by the women in order to contain their situation or endure the effects of the fistula on them.
CHAPTER ONE

INTRODUCTION

1.1 Background to study

Obstetric Fistula (OBF) is an abnormal opening between a woman’s vagina and bladder (VVF) and or rectum (RVF) through which her urine and or faeces continually leak (World Health Organisation, 2016). The most common cause of OBF is obstructed and or prolonged labour. Predisposing causes are poverty, poor-health seeking behaviours, paucity of skilled birth attendants, and poor obstetric care services (Ghana Health Service, 2015). According to the Fistula Foundation (2016), the root cause of obstructed labour is stunted growth especially in the developing world, where a girl’s pelvis may not fully develop before she starts childbirth. Lengthy obstructed labour frequently ends merely when the foetus expires and decomposes and is finally conceded from the mother. In most cases, the mother develops bruised pelvic tissue breakdowns, leaving a hole or fistula, between nearby organs.

Obstetric fistulae can generally be avoided by postponing the age of first pregnancy, terminating hazardous traditional practices such as female genital mutilation, early marriage, and by opportune access to appropriate obstetric care. More than 2 million young women live with untreated OBF in Asia and sub-Saharan Africa (UNFPA, 2016). World Health Organization approximates that 50,000–100,000 new cases occur every year (WHO (2014). About 90% of these cases are due to difficulties of lengthy obstructed labour (Hassan & Ekele, 2009). Compounding this disastrous physical trauma, in nearly all cases (Press, 2014), the woman must cope with the loss of her baby (Hassan & Ekele, 2009).
Stigmatization leads to social consequences of obstetric fistulae, which include divorce, rejection and isolation by family and community owing to the uncontrollable dribble of urine and/or faeces and the associated odour. Fistula also leaves women with few opportunities to earn a living, hence worsening their poverty (Mselle et al., 2011). Moreover, the traumatic labour may also lead to imminent incapability to conceive. (WHO, 2014). The demise of the baby, the inability to carry a live child, and the humiliation that accompanies fistula results in significant negative psychosocial and emotional outcomes (WHO, 2014). This study seeks to explore the experiences of women living with obstetric fistula in the Mfantseman Municipal Area (MMA) in the Central Region (CR) of Ghana. In Ghana, it is estimated that about 1,300 new cases of OBF occur every year (GHS, 2015 UNFPA, 2015). Though the cases are from all the regions, the greatest burden of the disease is found in the three northern regions, followed by the CR. It has been reported that surgical repair lags behind the disease load owing to few skilful surgeons (Fistula Foundation, 2016). This study therefore seeks to explore the experiences and coping tactics of women living with OBF in the MMA. Research report from Bangladesh reveals that women with fistula were always preoccupied with hiding their condition and as a result, they had to think about every movement that they make (Blum, 2012). The results will contribute to literature; inform policy and intervention programmes to improve the management of the condition, and support women living with obstetric fistula.

1.2 Problem statement

Though OBF has adverse impact on women, families and society, it is one of the most neglected morbidities of childbirth. An OBF is an abnormal opening between a woman’s vagina and bladder and/or rectum through which her urine and/or faeces continually leak
(WHO, 2016). It is expected that more than 2 million young women live with untreated obstetric fistula in Asia and sub-Saharan Africa (WHO, 2016) including Ghana. However, treatment capacity is limited to approximately 6,000 to 7,000 women per year (Royal college of Midwives, 2011).

Untreated OBF leads to severe medical, psychosocial and economic consequences which include divorce, neglect and isolation by family and community owing to the uncontrollable seepage of urine and or faeces and the associated smell (Mselle & Kohi, 2015). It also increases poverty since it leaves women with few opportunities to earn a living. Moreover, in nearly every case of fistula, a baby is stillborn and this may lead to future inability to conceive. Infertility may be a result of the traumatic labour as is stillbirth. These factors increase vulnerability to stigma, resulting in emotional stress (WHO, 2014).

According to the WHO, (2013), 15% of all pregnancies result in direct obstetric complications. Between the periods of 2011 and 2014, 1538 cases of OBF were recorded in Ghana (UNFPA, 2015; GHS, 2015). According to Ghana Health Service (2015), only 40% of the cases were repaired. Moreover, the distribution of OBF cases in Ghana indicates the CR is the second highest region with OBF incidence after the Northern Region (17.3% and 51.3% respectively). Out of the 15 districts with records of OBF in the CR, the MMA recorded the highest (23.1%) cases in 2014.

Despite the burden of OBF in the CR, not much research (Sullivan et al, 2016) has been done to examine the experiences of these women, particularly in the MMA. This study therefore seeks to explore the experiences of women living with OBF in the MMA in order to inform policy formulation and the development of appropriate interventions to help them manage the condition.
1.3 Research questions

1. What is the knowledge of women with fistula regarding the development of their condition?

2. What are the experiences of women living with fistula?

3. What are the coping strategies of women living with fistula?

1.4 Objectives

1.4.1 General Objective

The general objective of the study is to explore the experiences of women living with obstetric fistula in the MMA and their coping strategies.

1.4.2 Specific Objectives

1. To determine the level of knowledge of women regarding development of obstetric fistula

2. To examine experiences of women with obstetric fistula

3. To explore how obstetric fistula patients cope with the challenges they face

1.5 Justification

Assessment of the level of knowledge with respect to causes of OBF among women in the Mfantseman Municipal Area would highlight the knowledge gaps among these women. The results of our study will reveal specific areas of OBF, which need awareness creation to address these gaps and inform policy development to help women cope with their condition and better manage the negative experiences.
Additionally, when the challenges women with obstetric fistula face are identified, relevant fundamental determinants such as poverty, poor transportation systems, which invariably contribute to the social, economic, physical, psychological and emotional challenges they have after the fistula developed will be addressed. Addressing these challenges may improve the overall quality of life of the OBF patients.

Moreover, it is estimated that results from the study based on how OBF is developed and patients’ coping strategies with the challenges they face can inform efforts at OBF case detection and help address gaps in the current implementation of obstetric fistula programming.

Lastly, no study on the experiences of OBF women has been conducted at the study site, which is one of the key institutions where fistula repair is conducted. Lessons learnt will be relevant to other hospitals. The findings of this study will contribute to existing literature on OBF.

1.6. Outline of the dissertation

The study consisted of six chapters. Chapter One provides the introduction to the study, comprising background information, problem statement, justification, general objective, specific objectives, and research questions. Chapter Two covers the review of relevant literature. Chapter Three contains the methods that were used to carry out the study. Chapter Four examines the outcomes of the study. Chapter Five discusses the results of the study whilst chapter six presents the summary of the study results, conclusions, and recommendations drawn.
CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter examines academic literature on the subject matter and important published studies by other researchers relevant to this study. The literature review is structured around the objectives.

2.1 Obstetric Fistula as a Global Burden

Obstetric Fistula (OBF) is an abnormal opening between a woman’s vagina and bladder and/or rectum through which her urine and/or faeces continually leak (WHO, 2016). The WHO (2016) approximates that, worldwide, over 300 million women presently suffer from short or long-term difficulties rising from pregnancy or childbirth, with about 20 million new cases emerging every year. According to the World Health Report (2016), half a million young women die from these difficulties each year with the majority of these deaths occurring in developing countries. This is attributed to obstructed and/or prolonged labour coupled with poor health-seeking behaviours, poor health referral systems, lack of awareness, poor transportation systems, lack of skilful birth attendants, and insufficient obstetric care services (GHS, 2015). As a result, the survivors of these complications may develop OBF.

More than 2 million young women live with untreated OBF in Asia and Sub-Saharan Africa and between 50,000 and 100,000 women worldwide develop obstetric fistula each year (UNFPA, 2016). According to Waaldijk, (2004) and Hassan & Ekele, (2009) over 85% of OBF cases are caused by lengthy obstructed labour in the developing countries.
According to the WHO, (2006), the persistence of obstetric fistula in low-resource backgrounds is one of the best noticeable indicators of the huge gap in maternal health care between the industrialized and evolving world. Ghana is not an exemption from this OBF burden.

2.2. Obstetric Fistula in Ghana

In Ghana, between the period of 2011 and 2014, a total of 1,538 patients with vesico-vaginal fistula (VVF) accessed services, with the Northern Region recording the highest number (40.1%) of recorded OBF patients (GHS, 2015). Moreover, according to the GHS Report (2015), there are between 711 and 1,352 new cases of OBF developing in Ghana each year. People suffering from the disease are socially isolated and thus difficult to locate. Studies by Okoyei et al, (2014) recorded that some people view this disease as a sexually transmitted one and/or as a divine punishment.

It has however been noticed that OBF, which includes both vesico-vaginal fistula (VVF) and recto-vaginal fistula (RVF), represents a critically important but largely neglected problem in the field of reproductive health (GHS, 2015). The OBF is seen to persist into the future as a public health problem although it is preventable (Kalembo & Zgambo, 2012)

2.3 Challenges faced by women living with Obstetric Fistula

Obstetric fistula (OBF) is a condition that results from prolonged obstructed labour when the head of the baby is not able to pass through the pelvis of the woman. This creates an opening between the bladder and vagina or the rectum and the vagina. This causes the woman to seepage either faeces and or urine. OBF is a problem common in women of reproductive age across the world particularly in emerging nations. In developing countries, over 85% of OBF cases are triggered by prolonged obstructed labour
(Waaldijk, 2004; Hassan & Ekele, 2009). This could result in so many challenges, which may include the following:

2.3.1 Psychological and Emotional Challenges

Studies conducted by Ahmed and Holtz (2007) and Blum (2012) to scrutinize the psychosomatic and sensitive situation of women who develop OBF and those who mourn the death of their baby revealed that these women go through the trouble of having to struggle for their individual lives. This leads to a diminished participation in community life as well as a low self-esteem. The same authors observed from a meta-analysis of the results, that about 85% of the women who developed fistula lost their foetus from the delivery that caused the fistula. In Nigeria for instance, 33% OBF women who had fistula were secluded from their relations while 51% were not happy with their lives (Ahmed & Holtz, 2007). Most women lose their self-esteem and are easily stressed, anxious and angry. These place them through a reliably overwhelming psychological ordeal (Cook et al, 2004). These women commonly become socially invisible because of the abandonment by spouses, family and the community.

2.3.2. Socio-Cultural Challenges

Women with OBF are left with no choice than to cope with their situation (Kabayambi et al., 2014) in the absence of access to surgical repair. These coping strategies comprise eating and drinking only when it is needed, bathing regularly, using perfume and powder, putting calamine lotion on the sores surrounding the genitals and thighs, and using old pieces of cloth that are torn into shreds as pads (Ghana Health Service, 2015). These conditions affect their daily routine.
According to the Ghana Health Service Report (2015), higher rates of fistula in many developing nations are not only due to poverty, but also due to the influence of some cultural practices on women’s status, health, and welfare. One of the damaging cultural practices seen in some communities is the act of giving women lots of water to drink during labour. A full bladder according to Cook et al., (2004) has a higher tendency to cause fistula during eviction of the baby. Labour may at times be excessively prolonged, since accessible care may not be culturally tolerable in certain communities. For instance, certain communities would not allow a male health worker to deliver care to a pregnant woman in labour (Cook et al., 2004).

2.3.3. Economic Challenges

In addition to the psychosomatic pain it come with, obstetric fistula also levies enormous monetary burdens on sufferers and their families. Lack of cash or draining of scanty resources, lack of family backing, and long distance to health facilities were some of the reasons why women living with OBF are not easy to locate as noted by Kazaura et al., (2011).

The postponement of OBF repair may equally expose patients to a diminished social, mental, medical, and emotional status due to the spiteful difficulties accompanying the faecal or urine incontinence. This may ultimately lead to social withdrawal or exclusion (Murray et al., 2002).

The breakdown of marriages due to having OBF has been reported (Kabayambi et al., 2014). In addition, loss of children, seclusion, and lack of gainful employment are protuberant challenges, which increase the stress level for the affected women and could lead to loss of identity (Mselle et al., 2012). Beyond the individual woman, the families
may also experience stigma due to the status of the woman with OBF. This is called caregiver stigma (Kabayambi et al, 2014; Jarvis et al, 2017).

2.3.4 Medical Care Challenges

According to Ahmed & Holtz, (2007), 80% of women who develop fistula suffer from chronic skin diseases as a result of the direct irritation of urine. Okoye et al, (2014) observed that OBF women may develop amenorrhea, vaginal stenosis, childlessness, bladder calculi, infection and foot-drop, which are caused by neurological injuries. These women develop sores and lesions around their thighs caused by the continuous urine incontinence and rubbing.

Furthermore, according to Kabayambi et al, (2014) injury by providers and negligence were cited by the women and their caretakers among the perceived causes of some of the medical care challenges. The association of OBF with medical injury is valid (Wall, 2006). Although health workers are implicated, the most common cause of OBF stems from obstructed labour and delay during labour (Keri et al, 2010; WHO, 2012). These show that there is the need for further sensitization of communities on the causes and prevention of OBF and other labour-related complications. The underlying reason however could be the ineffective health care system (Murk, 2009). According to the Ghana Health Service Report (2015), shyness and financial difficulties were cited as the main reasons why women with fistula hesitate to seek medical attention. OBF women may not be allowed to seek medical care by in-laws to avoid the stigma and discrimination against their family. Some in-laws believed OBF is a condition that should be kept secret (Ghana Health Service, 2015).
2.4 Chapter summary

This chapter reviews existing literature in relation to the subject under investigation. This is in order to identify what has been done in the subject areas to identify gaps in the existing literature. Chapter Three presents the methods employed in conducting the study.
CHAPTER THREE

METHODOLOGY

3.0 Introduction

This section presents the methods that were employed to carry out the study. It discusses the research design, study area, study population, participants, selection of participants, data collection method, data analysis, and ethical considerations.

3.1. Research Design

This is a qualitative cross-sectional study, which used in-depth interviews to explore the experiences of women living with obstetric fistula.

3.2. Study Area

The study was conducted in Mankessim within the Mfantseman Municipal Area (MMA). It was selected because it has the highest incidence/prevalence of OBF in Southern Ghana and the second highest in the country. The MMA is in the CR of Ghana and located along the Atlantic coastline. It extends from latitudes 5° 7’ to 5° 20’ north of the Equator and longitudes 0° 44” to 1° 11” west of the Greenwich Meridian, stretching for about 21 kilometres along the coastline and about 13 kilometres inland. It covers an area of 612 square kilometres. The MMA shares boundaries to the South with the Atlantic Ocean, to the North with Ajumako Enyan Essiam District, to the East with Gomoa West District, and to the North West with Abura Asebu Kwamankese District. Mfantseman has five sub-districts: Saltpond, Mankessim, Anomabo, Biriwa and Dominase. The study was conducted at Mercy Women Catholic Hospital in the Mankissim sub-district within the Mfantseman Municipality. The district was chosen since out of the three health facilities
it has, Mercy Women Catholic Hospital located in Mankessim is the only one that treats OBF. Together with the other health facilities – Mankessim Health Centre and Market CHPS – these facilities serve a population of 41,605 out of the MMA’s 173,353, making the sub district the second most populous in the MMA. The majority (9,985) representing 24% of the population are women within the reproductive age (15-49 years). The total number of pregnancies recorded in the MMA is 1,666 in 2015 (Mfantseman District Health Management Team, 2015). Mercy Women Catholic Hospital reaches out to a total population of 8,900 comprising 1,869 adolescents (10-19 years) and 2,136 Women in Fertile Age (WIFA) (Mfantseman DHMT, 2015).

Figure 3.1: Map of Mfantseman Municipal Area

3.3. Study Population

The study population included women living with OBF who had reported to the Mercy Women Hospital in the MMA awaiting surgery. The study population consisted of women aged 15-50 years with a history of untreated OBF for six months or more. Women who developed fistula for less than six months were excluded from the study.

3.4.1. Selection of Participants

The study participants were selected using a combination of purposive and snowball techniques. Thirty-two participants were recruited in all: 10 community-based and 22 facility-based. Participants’ contact addresses were used to trace them to their communities. This was followed by snowballing seeking referrals from the initial participants. Purposive sampling was employed because we considered essential characteristics of study participants that were relevant for the study in addition to different backgrounds in order to have a fair representation of the target population. The essential characteristics that were considered include age, marital status, educational background, parity, occupation, religion and place of delivery and history of treated or untreated fistula.

3.5 Data Collection

In-depth Interview (IDI) was used to collect data. This data collection approach was chosen because it helps provide more information on sensitive issues, gives a good understanding of the participants, and is guided by open-ended questions. It helps the researcher to collect difficult, truthful, and passionate data that might otherwise not be obtainable through questionnaire or other quantitative methods.
The interview was divided into four sections and lasted for about 40–60 minutes. The first part lasted for 10 minutes. The questions focused on respondents’ background characteristics such as age, marital status, education etc. The second part covered their knowledge about how they developed OBF. The third part of the interview focused on participant’s experiences at home and the community in relation to the difficulties they face, and their understanding or perception of their experiences. The fourth section covered how the women living with OBF coped with their condition. In order to minimize respondent bias and the risk of reactivity whereby participants could hold back information in the presence of the interviewee, open-ended questions were arranged to follow the cues from participants. This enabled a full description of their experiences with obstetric fistula. The IDIs were carried out at the participant’s preferred place devoid of noise or disturbance. Interviews were audio recorded with permission from the participant.

3.6 Data Analysis
The data was analysed as follows. First, all the audio recording were transcribed verbatim and translated into English by an expert. Secondly, coding was done to identify participants’ words, phrases and sentences relevant to the study’s aim and answer to the questions. Thirdly, the codes were sorted into categories. Finally, themes were identified and the categories were arranged under them. Significant statements were clustered into themes, forming the “architecture of the findings” (Padgett, 2008) and were used to describe participants’ experiences with OBF and the context that influenced how the participants experienced the phenomenon.
3.7 Data Storage / Data Protection

The soft copy of audio tapes and transcribed data were locked on a computer using a password and the hard copy was locked in a cabinet, accessible only to principal researcher and supervisor.

3.8 Ethical Consideration

Ethical clearance was obtained from the Ghana Health Service Ethics Review Committee (GHC-ERC: 17/02/17). Participants were given sufficient information about the study and told that participation was entirely voluntary. They were also informed about the option to discontinue their participation without any adverse consequence. Participants were assured that this work does not expose them to any harm. There were no potential risks or benefits directly to study participants. However, the benefits of the research findings when harnessed and implemented would benefit participants and all women during delivery and after OBF repair.

Utmost privacy and confidentiality was maintained. Written informed consent forms (Appendix 1) were given to participants to sign, however, the consent form was interpreted in the local language and read to participants who could not read or write and verbal consent obtained from them.

An introductory letter was obtained from the Department of Population, Family and Reproductive Health (PFRH) of the School of Public Health (SPH) and presented to the Central Regional Health Directorate for introduction to the head of the hospital and hospital authorities for permission prior to conducting the study at the facility.
CHAPTER FOUR

RESULTS

4.0 Introduction

This section presents results of the in-depth interviews. The results are presented in five main sections: socio-demographic characteristics of participants, perception of OBF, experiences of women living with OBF, their coping strategies, and summary of the results.

4.1. Socio-demographic characteristics of study participants

The descriptive statistics in table 4.1 indicates that all the participants profess the Christian faith. The majority 11 (34.3%) of the women interviewed were between the ages of 41 and 50 years, only 1 (3.13%) was 61 years and above and none was 20 years or below. Regarding the place of residence, 21 (65.6%) participants were from urban communities while 11 (34.4%) were from rural communities. Also, majority 17 (53.1%) of the participants had no formal education, 7 (21.9%) had primary level education and only 3 (9.38%) had senior education and none had tertiary education. The analysis also revealed that half 16 (50%) of the women were married, 15 (46.9%) were single and only one representing (3.1%) was divorced.

In terms of number of children respondents had, the results show that none of the women had more than five children. The majority 18 (56.3%) of them had between 1-3 children, 5 (15.63%) of the women had between 4-5 children and 9 (28.13%) had no child.
Table 4.1: Socio-demographic characteristics of study participants

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
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<tr>
<td>21-30</td>
<td>8</td>
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<td>31-40</td>
<td>10</td>
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<tr>
<td>61</td>
<td>1</td>
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<td><strong>Residence</strong></td>
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</tr>
<tr>
<td>Urban</td>
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<tr>
<td><strong>Marital Status</strong></td>
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</tr>
<tr>
<td>Single</td>
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<td>50.0</td>
</tr>
<tr>
<td>Divorced</td>
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<tr>
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</tr>
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<td>JHS</td>
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<tr>
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</tr>
<tr>
<td><strong>Religion</strong></td>
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<td>Christianity</td>
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<td>100</td>
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<tr>
<td><strong>Number of children</strong></td>
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<tr>
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<td>15.6</td>
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<tr>
<td><strong>Occupation</strong></td>
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<tr>
<td>Unemployed</td>
<td>6</td>
<td>18.8</td>
</tr>
</tbody>
</table>
4.2 Perception of Fistula

When study participants were asked during in-depth interviews how they would describe their condition, the responses were varied. Some women describe their condition in terms of physical manifestations as follows:

_I am not able to control my urine from coming out as a normal person would do. The urine just flows out without my knowledge and this is what happens to me all the time. Therefore, I simply see myself as leaking urine._ (27-year old woman)

_Regarding my condition, I don’t know what to say about it. The urine is just coming out all the time and I cannot do anything about it. I leak urine all the time._ (35-year old woman)

_I know there is a hole in my bladder through which the urine passes all the time. Therefore, I have no control over it when there is urine in the bladder._ (55-year old woman)

However, most participants described their condition in light of social damage suffered as the result of the disease. For instance, some of the expressions from participants include:

_This condition is a disgraceful disease and no person deserves to live with it. I can’t even think of how to describe it that as a woman you are not able to pass urine when you want to, but rather the urine comes out just like that._ (36-year old woman)

_My condition is a disgraceful condition that prevents me from going to public places or social gatherings because you do not know when the urine will come and you will be wet. It is a disease of shame and I will not even want to see my enemy surfer for it._ (33-year old woman)
Moreover, some of the women view their condition as an accident whilst another described it as uncomfortable as illustrated below:

*With regard to my situation, I think it is an accident, which can happen to anybody and nothing can be done to prevent it. Otherwise, why is it that other women deliver without getting something like this? (45-year old woman)*

*I think something went wrong because this is my fourth delivery and I have never experienced this before. That is why I said it was an accident, which occurred during delivery. (40-year old woman)*

Other participants simply described the OBF as uncomfortable as illustrated below

*There is nothing more uncomfortable than living with this condition. You don’t have peace of mind because all the time you are worried about this disease. It is even worse when you are outside. (25-year old woman)*

*This disease has really made me awkward. I leak of urine every blessed day. I cannot go among people with the fear that my clothes will get wet and the resulting odour. Because of this, I am always at home. There is no life for me outside my home. (56-year old woman)*

4.3 Experiences of women living with Fistula

To explore the experiences of participants regarding their condition, several questions ranging from how fistula has affected their personal lives to how the condition has affected their interaction with the larger society were posed during in-depth interviews.
4.3.1. Living with fistula and personal happiness

The results show that though OBF affected women individually and in numerous ways, there are many similarities in the experiences of women living with fistula. Many participants were unhappy with their condition to the extent that some of them develop suicidal tendencies and ideations, speaking virtually about committing suicide or regretting to have been born as illustrated below:

*It has made me unhappy in life and when there is an event, I cannot participate fully. This has really affected my life due to the stench and the way people look at me as if I have some kind of strange disease condition. Sometimes I wish I were dead.* (54-year old woman)

*I am not happy at all. Every morning when I wake up the first thing I do is to fetch water and bath before I can do anything else for the day. It has affected me to the extent that I even wished I were dead since I have taken a lot of medication but none worked for me.* (38-year old woman)

*This problem has really affected me a lot in life especially how people treat me especially how my father and my stepmother talk to me because of this problem. That I always smell of urine really disturbs me a lot in life. I wish I were not born into this world.* (28-year old woman)

4.3.2 Experiences of living with fistula and social life

To some participants their social life is affected, as they are not able to mingle with other people. They are isolated and unable to interact with their community members. Hence, they feel lonely on daily basis with limited movement about their environment. The experience of isolation can be deduced from the following expressions by participants:
Since I got this problem, I cannot go near places where there are many people.
This is because when I go close to people, I really smell. They start moving away from me because of the odour that is why I am always at home. (50-year old woman)

Since I developed this problem, I cannot go anywhere. I have to stay at home all the time. Even if I need to buy something from the market, I am not able to go. This is because I develop many blisters between my thighs when my rugs get wet while I walk with it. I have to wait on my children to return from school before they go and get it for me (40-year old woman).

When you get this problem, it makes you think a lot. That is you cannot go among people. Then the clothes that you use smell of urine all the time and you are always not even happy to live in this world. Sometimes you need someone to share your problems with but with this condition, people shun your company and you become an outcast. (33-year old woman)

4.3.3 Married women living with fistula
Participants expressed their views regarding how fistula has affected their relationship with their husbands or partners. Some of them recounted with pain how they were abandoned by their married partners without social and financial support. For example:

The man with whom I had that baby who caused this problem left me. Then this present one when he realized I have this condition, he never came back. When I told him I was pregnant, he told me he is not ready for any child. He does not support me financially at all. (32-year old woman)
That man I do not know where he is; about twenty-five years. He left me immediately I developed the condition. As husband and wife, we were supposed to be happy together with the birth of our child, but here no, the baby died. I developed this terrible condition. I am supposed to go through it alone. I only pray to God someday I shall be cured of this condition. I have never set my eyes on him again. (34-year old woman)

This was my second pregnancy so I knew labour had started, but my mother-in-law advised me not to rush to the hospital. I delayed at home. The next morning when I could not bear the pains any longer, I informed my husband and he brought me to the hospital. At the hospital, the midwife who examined me told me she did not hear my baby’s heart beat due to the labour pains. I did not believe her but after about 20 minutes I delivered and my baby did not cry. After three days, I realize I do not have the urge to urinate by myself. I informed my husband and that was the beginning of my plight. For twelve years now, I do not know where he is. He never supports me. (36-year old woman)

After losing my baby, as if that is not enough my husband also divorced me as though I caused the death of our child. He has even left the community maybe because he does not even want people to be seeing him as my former husband. Because that was my first pregnancy, I have not been able to get pregnant again; I am now seen as a hopeless person. I do not know where he is now (55-year old woman).

However, there were a few, who receive support from their husbands and partners. This category of women expressed their experiences in the following comments:
He supports me a lot but we do not stay together again. We separated when I developed this condition but he is around and he asks about me. He gives me words of encouragement and he has even promised to support me financially during my surgery. (32-year old woman)

He is still around me. He never left me and I think he is a good man because a lot of men cannot do what he has done so I always pray to become well again and make him happy (31-year old woman).

4.3.4 Living with fistula and prospects of marriage

For women living with fistula but are not married, they see their condition as a major hindrance to their getting a suitor since all men who express interest in marrying them flee upon discovery of their condition. The sentiments of participants in this regard can be seen from the following transcripts:

This urine problem has affected me a lot in that sometimes, a man would see me and proposes to me but I cannot accept it because of this problem. I know it and feel shy to say yes. Sometimes when I am desperate and accept, as soon as they have sex with me and they see the problem, they do not come back again. They do not even call me. This has really affected me in life (27 years old woman).

I am not sure what to say but it has really affected me. Yes because of this problem, I have never been able to marry again since I got this problem more than 20 years (40-year old woman). This problem has affected me a lot in life. It has delayed my marriage life because for eight years now no man is coming close to me. Those who are bold to come when they get to know the situation they leave me without coming back to my life. (29-year old woman)
4.3.5 Fistula and reproductive life

Women who had no children and desire to have some identify their condition as affecting their inability to have children. They express their frustrations as seen below:

*For twenty years now, I have been suffering from this condition and at my age, I still do not have a child. When I think about all these then I do not even know what to say.*

(43-year old woman)

*I have not been able to get a child and I think this condition has made it even worse because no man will like to come close to me to propose marriage to me. Even if a man approaches me, I cannot accept because he will get to know eventually and he will leave me and that will embarrass me more.* (33-year old woman)

4.3.6 Experiences of living with fistula and physical features of fistula

One common experience reported by participants was the distressing experience of getting wet and smelly due to the leakage of their urine all the time. The experience makes some develop sores in their genital areas, a situation they lament as a worrying experience they had to endure. Others expressed worry of having to wash their rugs all the time. This hinders their interaction with community members as some community members do not behave well towards them while others do. Examples of statements from the in-depth interview illustrating this experience can be seen below:

*The way in which this problem has affected me is that when I walk around I get wet. Sometimes I develop sores at my private part. I have to use powder then as soon as I wear, the diapers (rugs) get wet very quickly and then I have to go home, then they laugh at me when they see that I am wet. Sometimes when I develop the sores those...*
who have sympathy say eh you are really suffering, then I will answer sister, it is not easy at all. (21-year old woman)

When you pile your rugs and do not have anybody to help you to wash them, which makes things worse. Yes when I got this problem at first I was very weak so I could not even wash. My auntie did all the things for me. Later, when my auntie is not around my husband used to help me with the washing. (36-year old woman)

4.3.7 Living with fistula and community perception

The perception of some community members about women living with fistula was found as an uncomfortable experience participants had to contend with. Due to their condition, members of the society see them as unfit and they talk about them in different ways. The following expressions show what study participants think of people’s perception about them:

Some people insult me and say that I am not faithful to my husband and that is why I got the problem. (45-year old woman)

It is my mother. One time I visited her and stayed overnight but because she knows I have this problem, even though the beddings did not get wet she still went ahead to bring all the beddings out to hang them on the lines and that really made me very sad. (28-year old woman)

When people come close to you they only want to gossip. In the village, those who know about my problem insult me with it. That I always smell of urine so for me any time I see somebody coming I go to hide myself. (33-year old woman)
Because of this even when you have not done anything wrong to people, when they want to insult you, they just start insulting their animal but you know indirectly it is you they are insulting. (24-year old woman)

4.3.8 Living with fistula and motherly roles

To explore the experiences of participants who are mothers, questions during the in-depth interviews sought to find out the extent to which fistula affects their role as a mother especially with respect to their relationship with their children after they developed the condition. The analysis revealed that some children are ok with their mother’s condition and offer them support while other mothers say their children were too young to understand their condition as indicated in the following statements:

There is no problem. My children are ok. Even though they are aware of it, they are not worried about my condition (36-year old mother).

My children give me a lot of support in my condition. They have become the pillar I lean on in all the troubles with living with this condition (61-year old woman).

When I change, they see but since they are young, they do not ask why. Therefore, I don’t know how they will react when they grow up. (28-year old mother)

For some mothers the condition has hindered their ability to take care of their children as expected of every mother hence their children are being maltreated by other women as seen here below.

I cannot work to provide for my children. My husband does not support my children and me. Even my aunt does not support me. She acts with my husband and even maltreats my children. (35-year old woman)
I am not able to fend for my children the way I would have liked to. They always encourage me and say it shall be well. (30-year old woman)

### 4.3.9 Living with fistula and interpersonal relationship

In terms of how people behave towards women living with fistula, the study found that the experiences of study participants were different. While some women reported that people behave normally towards them regardless of their condition, other participants indicated that people behave towards them negatively.

Some give me words of encouragement that it shall be well and they show a lot of concern. (32-year old woman)

Some people tease me with this condition. They behave a bit strange to me and look at me in a funny way. I don’t know what they think of me as if they are immune from this condition. (37-year old woman)

They shun my company as if they have never known me. They don’t even want to talk to me and when you greet them they don’t want to respond (33-year old woman)

To some women the way people perceive and behave towards them as a result of their condition is not limited to them alone but also extended to their family members. For instance, a participant expressed her sentiment as follows:

This condition has completely changed the way people behave towards me. It has even affected my mother’s business so she has now moved to a different community in order to sell her fish so that she will be able to support my siblings and me. (24-year old woman)
4.4 Coping strategies of women living with fistula

The study sought to examine how study participants cope with negative experiences resulting from their condition. These include negative experiences relating to their social or interpersonal relationships with individuals and community members, negative psychological experiences such as suicidal ideations and negative experiences seen in the physical manifestations of signs and symptoms of the condition requiring medical attention.

4.4.1 Coping with negative reactions from social and interpersonal relationships

In terms of negative experiences arising from interpersonal relationship, participants gave varying responses as to how they manage and cope with such experiences. While some respondents indicated that they adopt more careful approaches in dealing with people, others just encourage themselves and move on with their lives while ignoring negative responses they encounter from people and hope that they will be cured one day as seen in the following statements:

Since I developed this condition, I have been very careful how to approach people so that I don’t attract negative responses from them. I know that with God, everything is possible. I have strong faith that someday I will get a cure for this problem. (30-year old woman)

Yes, I know my problem so I am very careful where to step. People are always ready to insult you with your condition so I have to be careful in dealing with them. (Woman with fistula aged 28)
Most of the time I sit and ponder over all what I go through then sometimes I conclude that if I do not forget about these worries I will die and leave these children with no one to take care of them. (46-year old woman)

Others simply hide from people and do not attend social gatherings including going to church. Examples of expressions of participants are as follows:

I am always at home. I do not go to church because people in the community tease me all the time. Once at church a woman suggested to me that it would be better I stay at home because, I always soil the seats I sit on during church. Moreover, because of the stench people cannot sit close to me. I alone occupy a whole church pew and that is not good so I should consider sitting outside or not to come to church at all. (A woman aged 49).

Some of the people who live near me, when they see me they do not want me to come close to them. So I also hide myself when I hear people are coming closer. (25-year old woman)

Before I developed this condition, I was very big. Now I have lost a lot of weight so now I do not feel comfortable to be among people because no matter how I dress up, it does not look nice on me so I have stopped attending gatherings. (A woman aged 47)

I am not able to go to places where people are gathered. Even in the house where I live, when there are people around in the compound, I cannot sit with them. When I sit down I am okay, but as soon as I stand to walk then the urine dribble on my thighs, so I am always indoors. (A woman aged 41)
For some participants, they prefer to keep their condition as a secret. They will not tell anyone and they see such a decision as a way to be able to cope with it:

*Apart from my husband, I have not told anybody about it neither in the community nor in the house where I stay.* (A woman aged 28)

Meanwhile for some women with fistula, planning one’s daily activities in a manner so as not to encounter any embarrassment is key in coping with the condition as illustrated by a participant:

*When I have to take my child to the child welfare clinic, I always have to be there early so that I will be the first person to be seen so that I then come home straight from there to avoid any embarrassment* (34-year old woman).

### 4.4.2 Coping with continuous leakage of urine

With regard to exploring how respondents cope with physical signs and symptoms of their condition, participants were asked about how they manage with the continuous leakage of urine during in-depth interview sessions. It was obvious from their responses that participants employ various adaptive coping strategies in dealing with such an experience. However, the use of rugs and pampers was a dominant coping strategy reported by participants. The following expressions from respondents illustrate how women with fistula cope with continuous leakage of urine as a common feature of their condition:

*I leak a lot and because of that I do not like to drink water because the water cause me to leak a lot I use rugs and change them very often and this makes me a bit relieved.* (A woman 36 years old)
I use rugs, and if I have money I buy pampers. They are very expensive. I do not use them all the time. (A woman 26 year’s)

I buy old rugs, wash and use them since I don’t have money to buy pampers because they are expensive and if I want to be buying pampers then I won’t even have money to feed. (A woman aged 42).

As soon as I wake up in the morning, the first thing I do is I fetch water to the bathhouse to wash then I wash all my beddings and change them. (A woman aged 44)

I use rugs but before using the rugs, I would line my pants with small plastic bag then I would use the rugs and then wear short over it. (A woman aged 35)

Because I know my problem and the fact that I do not have the urge, I make sure I use pampers all the time and change as frequent as possible. I was using rugs but that also created a scene for me. I decided to stop but the use of pampers is also very expensive and every four days I have to buy a new pack (27-year old woman).

When I am at home I wash my rugs as soon as they are wet, but if I am travelling, I change my wet pampers very often. (27-year old woman).

4.4.3 Coping with discomfort

It is obvious from the responses of respondents that, their condition pose a lot of discomfort to them. Thus, it was crucial to explore how women with fistula handle the discomfort associated with their condition. It emerged from the analysis of their responses that the discomfort of living with fistula drives some participants to contemplate suicide. For some other participants, they cry or try to forget about it as a way of coping with it whilst some rely on God for strength to endure the discomfort.
Examples of responses from study participants relative to how they handle the discomfort of their condition are illustrated below:

*One time when I developed sores between my thighs I told my pastor now I really wish I am dead, then he told me to stop thinking like that but to know that with God everything in the world is well, then he gave me money to buy some cream to apply.*

(A woman, age 38)

*I am not happy at all. I cry a lot then sometimes I forget about it and stop crying.* (33-year old woman)

*I am not happy at all. I am always miserable. I cannot go among people; I always cry and pray to God to support me.* (A woman aged 38)

Moreover, some participants resign to fate and throw up their arms in despair as expressed by a participant as follows:

*It has happened. What else will I do except to always cry in life. I can only hope that one day healing will come from somewhere.* (A woman aged 37)

**4.4.4 Coping with smell**

The smell of urine is one of the distressing experiences of women living with fistula due to the constant leakage of urine. In a bid to explore how participants cope with the smell, they were asked during in-depth interviews to describe what they do in order to handle the smell. Several coping strategies were adopted by respondents as illustrated below:

*I wash every blessed day in life. I do not use ordinary soap for washing. I use Geisha sunlight and Dettol to handle those smell I do not wear my cloth twice.*
change it every day so that at least the smell will be minimized. (41-year old woman)

I only change and wash with soap because I do not have money to buy Dettol. I can’t be buying Dettol all the time because it is expensive for me. (A woman aged 31)

I buy scented soap and Dettol when I have money. When I use these to wash my rugs, it reduces the smell (23-year old woman).

4.5 Summary
Chapter Four presented the findings of the study with the description of categories and their themes supported with verbatim quotes from the study participants. Chapter Five will discuss the findings of this study with the existing literature regarding obstetric fistulae.
CHAPTER FIVE

DISCUSSION

5.0 Introduction

This section discusses the findings of the study. The results are discussed in relation to the findings of previous studies on the subject under investigation. This was done to identify similarities and differences in findings and to fill the gaps in the literature.

5.1 Socio-demographic characteristics of the study participants

The study participants were women living with fistula in the study area. Majority of them were between the ages 41 and 50 years followed by those between the ages 31 and 40 years. This finding contrasts the widely reported age of less than 20 years who develop fistula due to immature pelvis. For instance, a study done in Nigeria to determine the medical and social consequences of fistula, found that majority 72.5% of the women were between ages 10 and 20 years (Kabir, Iliyasu, Abubakar & Umar, 2003). However, it is unknown at what age these women developed fistula and subsequently how long they have been living with the condition.

The results of this study indicate that many of the participants had no formal education. This is similar to another study, which found that women with OBF were mostly uneducated and illiterates (Kalembo & Zgambo, 2012). Contrary to the finding that women with fistula were mostly in rural areas (Wall, Karshima, Kirschner & Arrowsmith, 2004), this study revealed that most of the women were in urban areas (rural 34.4% and urban 65.6%). The results however show that women in urban centres also stand the risk of developing fistula if they fail to utilize available antenatal or delivery
services early. Therefore, availability and access to antenatal services or the lack of it is a crucial determinant of fistula occurrence compared to rural–urban differences since there could be antenatal services even in rural settlements.

5.2 Knowledge of fistula development

The responses from participants of this study showed that they had a fair knowledge of how their condition developed. They associated the development of their condition with delivery and long hours of being in labour. They were also able to report the index pregnancy preceding their fistula.

Findings of this study show that women had their fistula through delivery. The results are supported by another study, which revealed that obstetric fistula is predominantly caused by long obstructed labour (Aahman et al., 2005). Additionally, most of them reported being in long hours of labour; more than 24 hours with some labour lasting as long as three days. This is consistent with findings that in developing countries, over 85% of OBF cases are caused by prolonged obstructed labour (Waaldijk, 2004; Hassan & Ekele, 2009). Wall et al. (2004), in their study also found that 96.5% of fistula development among study participants was associated with labour and delivery.

Contrary to findings by Tui et al (2007), who in their study found that women who develop obstetric fistula invariably delivered at home due to lack of emergency obstetric care with distance and transportation difficulties as key factors, this study found that many of the women with OBF delivered in the hospital. This, considering the fact that many of the women had their deliveries in hospital but developed the OBF, suggests that there could be gaps in the healthcare delivery systems such as not being attended to by a skilled health professional. This means that access to a hospital or healthcare facilities per
se is not enough. Instead, access to skilled maternal care during both antenatal care and labour could prevent the development of fistula.

Furthermore, the finding of this study is consistent with that of an earlier study that found that majority of women develop their fistula in the delivery process of their first pregnancy. Wall *et al.*, (2004) studied characteristics of women with fistula in Nigeria and reported that the typical fistula patient has certain features including developing fistula as a *primigravida*. A quarter of participants in this study reported that they developed their fistula in the delivery process of their first pregnancy.

5.3 Health seeking behaviour of fistula

The Ghana Health Service (GHS) has revealed that fistula can be repaired through surgery with a success rate of over 90% when carried out by a trained provider with the proper medical equipment (GHS, 2015). This is further supported by a WHO report that once fistulas occur, they require surgical repair since they usually cannot heal by themselves and over 90% of women with fistula can be cured with one operation and can resume an active and fulfilling life, including having additional children (WHO, 2006). Guided by this fact, the study sought to explore the health seeking behaviours of the women following development of fistula. The results showed that majority (78.1%) of them sought formal care. This indicates that participants were aware of the existence of treatment for their condition. This is contrary to findings by other studies that many women and/or their families, especially those who lacked skilled care during delivery, may not even know that a treatment exists for fistula (WHO, 2006). The difference could be because 90.3% of participants in this study had their delivery in the hospital, and may probably have been informed of the existence of treatment. However, none of the
participants who reported seeking for treatment at the hospital has undergone a surgical repair.

For the women who did not seek health care, the study found that some complained of lack of money as the reason for not seeking formal care while others reported that they were afraid. This supports Khisa and Nyamongo’s (2004) finding that poverty and fear of the consequences of an unsuccessful repair usually keep some women living with fistula away from seeking formal care to treat their condition. Interestingly, none of the study participants reported seeking traditional or herbal treatment for their condition.

5.4 Perceptions about fistula

The study sought to examine the perception of study participants regarding their condition. The participants’ perception of fistula varies. Some perceive fistula in the light of the physical manifestations they experience on daily basis such as urine leakage. As a result, they have associated such physical signs with the disease and thus perceive and describe it in such terms. Unlike other disease conditions, which are seen as sickness, fistula is perceived by its victims as a disgraceful disease. Their perception of fistula may be largely informed by their perception of what they think people and society always say about their condition. Their perception may also be influenced by their experiences in daily interpersonal and social interactions. For instance, a study done in Kenya to understand the experience of women before and after fistula repair revealed that due to the constant urine leakage, and the associated smell, many women were called pejorative names such as „Mache esosera” (stagnant rain water)” or „mama mkojo” (mother of urine) (Khisa, Wakasiaka, Mcgowan, Campbell, & Lavender, 2016). Another study to assess the views of patients on fistula in West Africa showed that the name “disease of the urine” was the generic term used for obstetric fistula in all the four languages in the research
area. The fistula patients, however, disliked this simplistic stigmatizing denomination of their condition (Maulet, Berthé, Traoré, & Macq, 2015). Thus, it is possible that these experiences have contributed greatly to erode the self-worth of women living with fistula and hence compel them to perceive their condition in such derogatory descriptive terms.

However, contrary to the popular perception of fistula by the majority participants in this study as a disgraceful disease, another participant simply perceived her condition as an accident. Similar to this view, a study on views of victims of fistula about their condition in West Africa established that participants perceived fistula as a disease given by God; that is they got it by accident and that no one especially themselves could be held responsible for it. Hence, they see fistula as part of “the large category of natural or God’s illnesses. (Maulet et al, 2015)

5.5 Experiences of living with fistula
This study found that experiences related to personal happiness of women with fistula is that of sorrow and sadness. The severity of their sorrowful life is clearly manifested in their expressions of harbouring suicidal ideations to end their life of sadness. This finding is consistent with reports from other studies, which found that fistula victims live a life of sorrow. In a study conducted in Nigeria, about 33% of women with fistulas were psychologically depressed, and an additional 51% were bitter about life (Kalembo & Zgambo, 2012). Khisa et al. (2016) also found that a combination of issues ranging from stigma, isolation, financial difficulties due to diminished employability led to erosion of self-worth in women living with fistula and in many cases, led to psychological distress resulting in suicidal tendencies.
The social life of women in this study was found to be poor. Many of them reported isolating themselves in order to avoid being stigmatized by people and the larger society. This experience is common with women living with fistula across many parts of the globe. Khisa et al. (2016), found that women living with fistula experienced negative social interactions that initiated feelings of humiliation and distress. Consequently, they withdraw from social encounters because of stigmatization by members of their local communities.

Stigma is defined as an attribute that is deeply discrediting and that which reduces the woman from a whole and normal person to a tainted or discounted one (Goffman, 1963). Stigma was observed in three forms in this study: internal, external and caregiver. One type, internal stigma, occurs intra-personally when the stigmatized individual internalizes the negative stereotype; for example, the woman living with OBF may tell herself, “I am worthless”; I am unclean” (Link and Phelan, 2001). External (interpersonal) stigma is when stigmatized individual is treated differently during social interaction because of a negative stereotype.

Caregiver (interpersonal) when family members or other caregivers experience external stigma because of their relationship with a stigmatized individual.

Another study found that stigma against women with fistula manifested itself in various ways. This ranges from subtle to blatant discrimination and isolation. The stigma continues even after corrective surgery. The study further revealed that stigma was by their families and the community. The OBF victims are isolated and not allowed to participate fully in household chores or social activities. Similar experiences of women with fistula have been noted by Mafakhkharul and Begum (2007) who studied patients with vesico-vaginal fistula to assess the psychosocial effects of the condition on them.
They identified psychosocial problems such as feeling of embarrassment in the midst of others. Gbola (2007) also identified psychological experiences of women with OBF to include social isolation and worry over stigmatization.

Divorce and abandonment by husbands and partners are common consequences of developing fistula. According to reports in sub-Saharan Africa, more than 50% of women with fistula are divorced by their husbands (Kalembo & Zgmanbo, 2012). Another study in Nigeria, reported that 14% of patients were divorced by their husbands immediately after fistula occurred and 42% continued to live with their husbands. However, if the condition persists, 28% of the women were divorced and only 11% were allowed to stay in married homes (Kalembo & Zgmanbo, 2012). Married women who develop fistula are often returned to their parents’ home (Kalembo & Zgmanbo, 2012). These findings agree largely with the results of this study which showed that majority of the women reported being divorced and abandoned by their husbands following development of their condition. A few of them, however, reported having emotional support and financial support from their husbands.

For unmarried women with fistula, they see their prospect of getting married as a near impossibility as no man wants to come close to them. This confirms reports from a study that women who develop fistula may end up separated or divorced owing to their condition, while those who are not married may remain so (Khisa & Nyamongo, 2012).

Critical analysis of participants’ responses regarding their desire to have children, reveal that women living with fistula are deeply frustrated and feel hopeless. They see their condition as a limitation that undermines their reproductive ability. This result seems to confirm studies in two sub-Saharan African countries, which found that in Nigeria, women with unrepaired fistula have a spontaneous abortion rate of nearly 50%, whereas
the rate in those with a repaired fistula drops to 6%. The study also reported that in Kenya, almost 60% of women with repaired fistula had miscarriage and stillbirth and secondary infertility are common with women with fistula (Kalembo & Zgmanbo, 2012). Childlessness is so devastating in a culture where a woman’s status is largely determined by her reproductive functioning.

The physical problems presented by fistula constitute a major worry for women living with fistula. They reported having had to endure daily ordeals of urine smell, washing of their rugs, wearing and changing of rugs frequently, enduring development of sore within their perineal area, dealing with constant leakage of urine and being wet all the time. For many of them, the list of the physical challenges presented by fistula is endless. Other studies had also identified similar physical problems facing women with obstetric fistula. According to Mafakhkharal and Begum (2007), Bangladeshi women with obstetric fistula reported physical problems such as development of genital ulcers caused by the persistent wetness of the genital area and frequent itching leading to scratching among others.

Furthermore, dealing with community and societal perception of living with fistula is one of the bitterest experiences reported by women living with fistula globally. Participants in this study view their condition as the subject of discussion by community members. They feel condemned by society and described as unfit and outcasts. In the words of Ahmed and Holtz (2007), women affected with obstetric fistula are the most dispossessed, outcast and powerless group of women in the world. Although communities’ perceptions of women living with fistula may not be tangible, these perceptions greatly influence the lives of women with fistula.

In Ghana, performing motherly roles in families is an experience cherished by women. However, for women with fistula, the experience is different. They feel that their position
as a mother is shifted, since they are unable to perform all the roles expected of a mother. This study found that though their children had no issues with their condition, they feel incomplete as a mother since they are unable to take care of their children the way they would have done without the condition. This is due to their inability to engage in income generating activities due to the stigma and isolation they undergo. For example Khisa et al. (2016), found that some women value being able to contribute to the family income. Their inability to do so had negative impact on the family resources and demoralized the women.

5.6 Coping strategies of women living with fistula
Living with fistula as reported by women in this study involves devising various means to keep life going. For instance, in coping with societal stigma and negative reactions from individuals, some women are more careful in their dealings with people to avoid any inappropriate response, which may cause them embarrassment. Others just encourage themselves and move on any time they are confronted with negative reactions from people. Some others adopt hiding in isolation from people as the best way to cope with the ever-present societal stigmatization of their condition. In the case of women whose condition is not known to others, they believe keeping it as a secret is the only way to keep living with fistula. Other women also plan their daily activities in a way that they can avoid encounters likely to bring them embarrassment. This agrees with findings from Bangladesh that women with fistula were always preoccupied with hiding their condition and as a result, they had to think about every movement that they make (Blum, 2012).

Moreover, other women contemplated suicide at one point but never went on to execute their suicidal thoughts because of intervention from other people or their realization that it was not the best coping strategy. Similarly, a qualitative study of the experience of
obstetric fistula survivors in Addis Ababa, Ethiopia revealed that women with fistula use emotion-focused coping strategies such as isolating themselves or suffering in isolation, suicidal thoughts and attempts, positive subjective interpretation, and avoidance (Gebresilase, 2014).

In coping with the continuous leakage of urine, women reported various strategies. The most common and widespread strategy, however, was wearing of rugs. Few of them reported using pampers sometimes. The use of rugs was common because they are readily available compared to pampers which they have to buy. Women would prefer using the cossets for the continuous leakage of urine, but this is seen as an expensive coping strategy, which they cannot afford. This is compounded by their limited ability to engage in income generating activities as a result of their condition. Even with wearing of the rugs, some of them have adopted innovative strategies to deal with the constant leakage of urine by putting on plastic materials before the rugs to minimize the frequent change of wet rugs. This strategy though helpful, may predispose them to other medical consequences. A study in the Democratic Republic of Congo found similar results where women with fistula wore layers of cloth to absorb the leaking urine. The study further revealed that many women covered their rugs with a plastic bag to ensure that the urine did not leak through their clothing (Blum, 2012).

Surprisingly, some women reported that they limit drinking of water as a way of coping with the leakage of urine. This finding supports the results of an earlier study that women with fistula restrict intake of liquids and foods considered high in water content, to decrease the flow of urine (Blum, 2012). This may appear intelligent but the medical consequences of this strategy may be grave as they may suffer severe dehydration.
Finally, coping with the most distressing physical features associated with living with fistula such as the discomfort of wetness, itching and smell seems to be the most unpleasant. Participants of this study reported that they cope with these by frequent change of rugs and regular washing as well as using scented soap and powder. These coping mechanisms may seem inadequate to give them the needed comfort, but remain the only alternatives available to them until they receive a successful surgical repair of their fistula. These coping strategies were also reported in studies elsewhere that found that many women with fistula applied scented powders or perfume to cover the offensive odour, changed and washed their rugs frequently (Blum, 2012).

It was obvious from this study, that the process of managing the rugs was an ongoing preoccupation that involved washing and ensuring that they were properly dried, all of which required a tremendous amount of time. Besides, acquiring the soap, water as well as the scented powder and perfume brings additional financial burden on the women and these add on to the worries of women living with fistula.
CHAPTER SIX

6.0 SUMMARY AND CONCLUSION

6.1 Summary

This study explored the experiences of women living with fistula in the MMA. In-depth interviews were conducted to assess the experiences of the women with various aspects of their life. The study also explored coping strategies of women living with fistula.

The results of the study show that women living with fistula are confronted with stigmatization from society, which compels them to live a life of isolation and seclusion. They also face challenges with their marriage and reproductive lives, as well as not being able to engage in income generating activities.

The difficulties encountered by women living with fistula often drive them to harbour suicidal tendencies as a means of ending their struggle with fistula.

However, women living with fistula in the study area adopt various innovative and cost effective ways of coping with their condition including limiting water intake and the use of scented perfumes to cope with the constant urine leakage and the associated smell respectively.

6.2 Conclusion

The results of the study showed that women living with fistula in the study area are vulnerable to stigma and some live a life of isolation. They generally lack support from their husbands, are divorced or abandoned. The women also faced financial challenges
aggravated by the condition and their inability to engage in income generation activities owing to the life of isolation they live.

The study further established that majority of the women in this study developed their fistula during delivery when they experience long duration of labour between 24 hours to 72 hours. In addition, most of them develop the condition during the first pregnancy. Most of the women sought formal care following development of fistula but none has undergone a surgical repair at the time of study.

Women with fistula resort to various strategies such as washing of rugs and use of scented soap and perfumes to deal with the smell resulting from the leakage of urine. Some women also reduce their intake of water as a means of reducing the leakage of urine.

6.3 Recommendations

The study made in view of the findings, the following recommendations addressed to specific stakeholders.

6.3.1 Government

Given the neglected nature of fistula, the Government of Ghana should consider fistula as a societal problem, which needs social intervention. Government should provide free medical care for women living with fistula. This will enable women with the condition who are hiding and are unable to meet the cost of treatment have access health care services. The government should also support women with fistula financially to enable them meet the financial responsibilities of managing the condition and strengthen the fight against girl child marriage.
6.3.2 Ministry of health

The Ministry of Health (MoH) should take deliberate steps to train surgeons and midwives for posting across the country to provide requisite care to pregnant women. The MoH should also create health care facilities with the needed equipment, staff facilities with adequate and skilful doctors and nurses to treat women who develop fistula with surgical repairs across the country. Policies should also be developed by the MoH on education and awareness creation about fistula for implementation.

6.3.3 Ghana health service

As the policy implementation agency of the MoH, the Ghana Health Service should ensure that pregnant women are cared for by skilled health care professionals at all hospitals and healthcare facilities across the country. Ideally, a better education in maternity care and a more effective prenatal care could help avoid the problems of fistula in the majority of cases. Health promotion and education should be carried out frequently in all communities to educate women on the risk factors of fistula and hygienic practices fistula patient should adopt. Clinical Psychologists can be made available at district Hospitals and patients can be referred to them free.

6.3.4 Civil society organizations and philanthropists

Civil society organizations must support government efforts by reaching out to women with fistula in order to support them to receive surgical repairs for their condition. Sensitization and awareness creation should also be undertaken to educate women and young girls on the risk factors of fistula as well as support the fight against early marriage of the girl child. Philanthropy is a possible source of support for women who fall outside the mainstream issues.
6.3.5 Future research

There is the need for further research to explore issues related to lifestyles during pregnancy, how these can affect fistula borne labour and how long the women delay before seeking formal care. This would help to pinpoint more clearly, where the problem lies.

There are implications linked to some of the practices adopted by women living with fistula to cope with the challenges posed by the disease, and to establish best coping strategies.
REFERENCES
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APPENDICES

APPENDIX 1: INFORMED CONSENT FORM FOR PATIENTS

Title: Experience of women living with Obstetric Fistula in the Mfantseman Municipality

Principal Investigator: Rose Mantey

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Introduction

Dear Participants, Obstetric Fistula (OBF) is an abnormal opening between a woman’s vagina and bladder and/or rectum through which her urine and/or faeces continually leak. This study seeks to explore the experiences of women in the Mfantseman Municipality of Ghana in order to help inform policy on the appropriate strategies to manage the condition. I hope you will help us to make this study a success.

Procedure, Possible Risk and Benefits

Questions will be asked based on utilization of skilled delivery in the Mfantseman Municipality. No risk or discomfort is foreseen concerning your participation in this research apart from your time that will be spent on answering some questions, which will take about 40 – 60 minutes. There is no direct benefit to participant; however, the outcome of this study will be used to help inform policy on the appropriate strategies to manage the condition.
Right to Refuse and Confidentiality

Your participation in this study is voluntary and you are at liberty to withdraw at any time. There will not be any penalty in opting out of this study or not answering any question. However your opinion will enable us understand the deficits in the quality of care of medical imaging services and also help us address any challenge in delivering these services. This study has been reviewed and approved by the Ethical Review Committee of Ghana Health Services. Participant personal identification such as names and address will not be written on questionnaire. Each questionnaire will be given a unique identification number.

You may contact me on the telephone number provided and email address or the

GHS/ERC Administrator, Hannah Frimpong (+233 243 235 225 or +233 507 041 223)
email: hannah.frimpong@ghsmail.org for any concern or question. Thank you.

Nana Abena Kwaa
Assistant GHS ERC Administrator

Mobile 0244712919 / Email: nanatuesdaykad@yahoo.com
PARTICIPANT CONSENT FORM

I have been thoroughly briefed on the entire methodology and significance of the ongoing study, which is being conducted by Rose Mantey. On my own free will, I hereby consent to be part of the study, based on my understanding of what the study entails.

I am doing this on condition that under no circumstance should any references be made to my actual identity or to any other person(s) after providing all the information requested from me for this particular study as promised by the researcher.

Respondent signature: …………………………….. Date ………………………………

Witness” signature: …………………………….. Date ………………………………

Researcher signature: …………………………….. Date ………………………………
APPENDIX 2: INTERVIEW GUIDE

EXPERIENCES OF WOMEN LIVING WITH OBSTERTRIC FISTULA

Objective: To explore the experiences of women living with obstetric fistula

1. Date (Day/Month/Year):__________
2. Patient’s Initials (optional): __________     3. ID of participant________
4. Staff initials (interviewer) ________

Demographics
The following questions ask about demographic characteristics (your age, where you live, whom you live with and how you live)

5. In what type of residence do you currently live?
   Rural / Urban
6. With whom do you live?
7. How old are you?
8. What is the highest educational level you have completed?
9. What is your marital status?
10. What is your occupation?
11. How many children do you have?
12. Religion
13. Where did you deliver?

Knowledge about fistula
14. How would you describe obstetric fistula
15. How did you develop fistula
16. How long were you in labour?
17. Which pregnancy caused the fistula?
18. Do you suffer from any other condition that occurred after the Fistula?

Health seeking behaviour
19. Did you ever try to seek for treatment?
20. If yes, where (specify)
21. If no, why

**Experiences of women living with fistula**

22. In what ways are you affected by obstetric fistula?

23. How has obstetric fistula changed the way people perceive you? Follow-up questions about the following places: House, Community, church, market etc.,

24. How has obstetric fistula changed the way people behave towards you?

25. How does fistula affect your interaction with your community members?

26. How does your present condition affect you as a mother?

27. How has fistula affected your relationship with your husband/partner e.g. sexual, financial support?

**Coping strategies (How the patients are able to manage negative experiences)**

28. How do you manage with the continues leakage of urine

29. How do you handle the discomfort in your daily life?

30. How do you handle the smell from the urine leakages?