

**A GROUNDED THEORY OF REGAINING NORMALCY: HEALTH SEEKING
BEHAVIOUR AND REINTEGRATION OF PATIENTS WITH OBSTETRIC FISTULA
IN KENYA**

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DECLARATION

This thesis is my original work and has not been presented for a degree or any other award in any other university.

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DEDICATION

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LIST OF ABBREVIATIONS

AMREF	African Medical and Research Foundation
ANC	Antenatal Care
EmOC	Emergency Obstetric Care
EOC	Essential Obstetric Care
GT	Grounded Theory Methodology
HSB	Health Seeking Behaviour
ICPD	International Conference on Population and Development
KDHS	Kenya Demographic and Health Survey
NGO	Non-Governmental Organisation
RVF	Rectovaginal Fistula
SDG	Sustainable Development Goal
SMI	Safe Motherhood Initiative
SRH	Sexual and Reproductive Health
UNFPA	United Nations Population Fund
VVF	Vesicovaginal Fistula
WHO	World Health Organisation

OPERATIONAL DEFINITIONS

In discussing the healing process of fistula patients, I have used certain terminologies that appear throughout my thesis. In the context of my study they are operationalised as follows:

Coping:

The strategies that women who suffer from obstetric fistula illness engage in and the resources they draw from to overcome the challenges brought about by the illness.

Health Seeking Behaviour:

The activities exhibited and patterns followed by women while seeking remedy after developing obstetric fistula illness.

Integration:

State in which the obstetric fistula patient starts a new life, away from previous social settings before fistula surgery. They forge new social relations and vocational occupations.

Normalcy:

Participants' perspective of what a return to normal life means to them.

Reintegration:

State which the obstetric fistula patient regains optimal physical, psychological, social and economic 'normalcy' akin to that before fistula illness.

ABSTRACT

Background: Obstetric fistula is a reproductive health problem causing immense suffering to 1% of women in Kenya. Formed as sequelae to obstructed labour, the women endure urinary and faecal incontinence, foot drop, social isolation, stigma, and psychological symptoms and endure great disruption to their socioeconomic wellbeing. Approximately 1200 women undergo free surgery annually.

Objective: The health behaviour of fistula patients and their penultimate reintegration after surgery remains undocumented. The purpose of this study was to explore the experiences of women seeking treatment during fistula illness and their return to normalcy after surgery in three VVF repair centres in Kenya. The study sought to answer three main research questions. 1) What key patterns of health seeking behaviour do women with obstetric fistula display in their quest for healing? 2) How do obstetric fistula patients cope with the illness? 3) What are the strategies that improve obstetric fistula patients' social reintegration?

Methods: Qualitative research methods were used to conduct the study. Grounded theory methodology was used to examine the health seeking trajectories of patients with obstetric fistula. Qualitative data was obtained through narratives with women after corrective surgery in two phases. In-depth interviews with family members and health care providers were also conducted. Initially, 121 interviews participants were conducted in the immediate period after surgery. In the second phase, interviews with 61 participants were conducted during community follow-up visits in their homes after 6-19 months postoperatively. Grounded theory processes of theoretical sampling, repeated measurement; constant comparative coding in three stage open, axial and selective coding; memoing, reflexivity and positionality were applied. The study was conducted over a 19 month period at a cost of Ksh. 1,340,115.

Results: Based on phase one results, an argument is made that the chronicity of fistula illness is presented in the narratives of women who live with the illness for years to decades, presenting physical, hygiene and moral challenges. Fistula illness introduces a crisis in women's life begetting feelings of shame. To regain normalcy, women respond by reaching out to family and the formal health care system. A composite pathway of health seeking behaviour generated is sequential, composed of seven key actors, with hospitals as key dispersers of women to alternative care providers. Health system failures are a key contributor to this pathway besides women's individual factors such as knowledge about fistula illness and contextual situations such as support of family and peers.

Based on phase two findings, an argument is made that after surgery, four possible outcomes of reintegration are presented, namely reintegration fully or partially back into their previous communities, not reintegrated or newly integrating away from previous social and family settings. These four possible outcomes are a result of interaction between enablers and disablers of the process of regaining normalcy, depending on the woman's individual and contextual factors. The results were used to develop a conceptual framework of reintegration of fistula patients and generate theory. The emerging substantive grounded theory on regaining normalcy for fistula patients is presented.

Conclusion: Grounded theory techniques were sufficient to investigate the processes of health seeking behaviour and the process of reintegration for obstetric fistula patients. In their quest for healing, obstetric fistula patients experience dysfunctional health seeking behaviour patterns. Further, their return to a normal life depends on eliminating disablers and strengthening the enablers of reintegration. The study recommends holistic programs delivering care to fistula

patients to hasten the treatment of existing cases and ensure return to normal lives to all patients treated using the conceptual framework of regaining normalcy for fistula patients.

CHAPTER 1: INTRODUCTION

1.1 Background to the study

My inspiration to conduct exploratory and later long term research on vaginal fistula came about in the most atypical of ways. Initially, as a graduate student at the Institute of Anthropology, Gender and African studies, University of Nairobi, I focused on reproductive health conditions that hamper women's participation in development and the gendered nature of such illnesses. The focus on women's illness was obviously informed by my background training in nursing and midwifery. I chose to conduct research on obstetric fistula as an illness that exclusively affected women and mused on what, besides biology could be so wrong to burden women inequitably.

At that point, the devastating nature of fistula illness captivated me. Telling the women's story in the most comprehensive way thus became my obligation— knowing too well how policies of the day demand scientific evidence. I thus proceeded from gendered aspects of fistula illness to understanding fully the women's experience of fistula illness and healing, and how women's reproductive health programs could holistically cater for their healing.

In this thesis, I proceed to introduce and discuss topic of the health seeking behaviour and the reintegration of patients with obstetric fistula in Kenya. The thesis is divided five main sections, namely, introduction, literature review, methodology, results and discussion. For easy readability and clarity of presentation, the results chapter is further divided into three main chapters corresponding to the three main study objectives. There are seven chapters, each with an introduction and body of the relevant content to the section.

But first, what is this illness, and why is it important? Obstetric fistula refers to an abnormal communication between the vaginal tract and rectum or between vagina and the urinary tract as a

result of obstructed labour (Gwyneth and Bernis, 2006). Ischemic lesions resulting from tissue destruction due to prolonged pressure by the foetus head during obstructed labour are the main mechanism leading to formation of obstetric fistula in women (Rochat, 2011). The ischemic lesion creates a hole between the reproductive tract and adjacent cavities. Communication between the vagina and bladder is referred to as vesicovaginal fistula (VVF) and is characterised by uncontrollable leaking of urine. Communication between the vagina and rectum is referred to as rectovaginal fistula (RVF) and is characterised by incontinence of faecal matter. During labour, other iatrogenic types of obstetric fistula occur due to tissue laceration during instrumental delivery, caesarean section or caesarean hysterectomy (Rochat, 2011). Both VVF and RVF may occur at the same time (FIGO, 2006). Other causes of vaginal fistula include rape, surgical trauma and cancer of the reproductive tract organs. This study focused on obstetric fistula.

Obstetric fistula is a distressing complication of labour and delivery that often results in distressing physical and emotional symptoms for women (Elneil, 2010). Women living with obstetric fistula face many physical, social and psychological problems (McFadden et al., 2011). Often, they are isolated and abandoned, living as outcasts especially when cultural beliefs attribute their condition to curses and evil spells. Such women may still face similar challenges after surgery. In a study at Kenyatta National Hospital by Khisa and colleagues, it was reported that women who are survivors of obstetric fistula tend to have psychological trauma and show signs of depression (Khisa et al., 2011).

Developed countries have eradicated obstetric fistula, compared to the low and middle income countries of the developing regions of Sub-Saharan Africa and Southern Asia (Cook et al., 2004b). Notably, women in the developed countries that have eliminated obstetric fistula have

better access to Essential and Emergency Obstetric Care. Developed countries have also reported significantly low maternal morbidity and mortality compared to the developing world (United Nations, 2010). The conditions under which women labour and deliver their babies are therefore directly linked to whether they develop obstetric fistula or not. For instance, a study conducted in Uganda reported that obstetric fistula is most prevalent in rural areas that have poor infrastructure and little access to emergency obstetric care (Kayondo et al., 2011).

Globally, it is estimated that more than 2 million women are living with obstetric fistula with an additional 50,000 - 100,000 new cases each year (WHO, 2005, WHO, 2010). In Kenya, the prevalence is estimated at 1% of women (KNBS, MOH, NACC, KEMRI, NCPD, 2015). Previously, a facility based study estimated the prevalence to be 1 in 1000 women a lower figure than the population based one, probably because not all women present for treatment at fistula repair facilities (Mabeya, 2004). The established prevalence however suggests that the problem currently affects about 200,000 – 250,000 women and provides a basis for planning for the needs of these women.

Recent collaborations between government hospitals, VVF specialist surgeons, University Teaching Hospitals and NGOs have led to the establishment of a VVF centre of excellence in Kenyatta National Hospital (KNH); on job training of doctors and nurses in care of VVF patients; and building capacity of regional provincial and level five hospitals to carry out continuous VVF surgeries. An estimated 1,201 VVF surgeries were performed under such collaborations in 2009-2010 (African Medical and Research Foundation, 2011). Dedicated fistula repair centres have also been established like that of Gynocare centre. Although the reported number of surgeries performed annually are a small proportion of the estimated women living

with fistula, there are hundreds of women who each year obtain treatment for fistula and return to the communities.

Many studies on obstetric fistula globally have focused on the period between surgical repair and healing with surgical approaches getting the most attention. A similar trend is observed locally, with few studies documenting the experiences of women living with obstetric fistula in Kenya (Ministry of Health Kenya and United Nations Fund for Population Activities, 2004). While studies have documented the challenges the women face, little is known on how patients seek to overcome these challenges, especially before surgical repair. There is also lack of specific approaches to social reintegration of patients who undergo surgical repair. There is lack of current research on the topic of health seeking behaviour and reintegration of obstetric fistula patients in Kenya.

1.2 Problem statement

Obstetric fistula continues to cause suffering to women in Kenya. The condition results from birth related injury to the vaginal wall, where the vaginal canal communicates with the bladder resulting in urinary incontinence or between the vaginal canal and the rectum causing faecal incontinence. Globally an estimated 2 million women suffer obstetric fistula (Gwyneth and Bernis, 2006) and in Kenya prevalence is estimated 1% (Kenya National Bureau of Statistics (KNBS) et al., 2015). The condition is treated by corrective surgery, a practice which has gained momentum over time in Kenya. However, little effort has been made to cater for social and psychological needs of patients with fistula. Specifically, the health seeking behaviour patterns of women suffering obstetric fistula and reintegration after surgery are two care issues that remain largely unexplored.

Obstetric fistula is still prevalent in Kenya indicating poor maternal health services and neglect of women's reproductive health. Current efforts in Kenya have mainly focused on surgical repair for patients suffering from obstetric fistula with great success. Corrective surgery is often the first step towards reintegration. An estimated 1201 VVF surgeries were done in the year 2010, and similar numbers are being treated each year, creating an opportunity for reintegrating the women back into the community. Evidently, surgical repair has led to a significant population of affected women who are ready for reintegration.

Living with obstetric fistula is fraught with challenges. First, women must be willing and ready to undergo corrective surgery within an environment whose support is not always guaranteed. Thus healthcare seeking among these women is likely to be negatively influenced and causes delays in care seeking. A recent study in a hospital in western Kenya indicated that 35% of the women had experienced incontinence for one to five years and a further 19% for over five years (McFadden et al., 2011).

Second, following surgery and upon discharge from hospital the women often return to the same social setting which has created conditions of stigma and discrimination. The women have to navigate this social environment in order to gain social acceptance. While interventions like surgical treatment for fistula patients are currently ongoing with great success, strategies to utilise family and community coping strategies in supporting fistula patients are yet to be investigated comprehensively. Questions arise as to how reintegration can be achieved, and what even is termed as reintegration and 'normalcy' for recovering fistula patients.

At recruitment phase, the study investigated the health seeking behaviour of obstetric fistula patients in their efforts to obtain healing. The focus was on the period from the point of illness

recognition to being attended to at a formal healthcare facility, the role of informal healthcare and folk medicine such as traditional healers and traditional birth attendants were also explored. The study conducted a follow up of a group of women upon discharge from hospital after surgery for a period of 6 to 19 months to determine their reintegration in their communities. The study sought to establish how women return to the social environment within the family and in the communities.

There existed four gaps in the study area selected. First, there was scarce data on the health seeking behaviour of obstetric fistula patients. Secondly, there was no existing reintegration framework for obstetric fistula patients. Third, there was a growing number of women obtaining fistula reparative surgery and discharged into communities with the assumption that reintegration would naturally occur. Finally, the fourth and overarching gap was in the approach within which holistic care can be offered to patients with obstetric fistula in Kenya in the current context. The research therefore aimed to answer the following research questions.

1.3 Research questions

The purpose of this study was to develop substantive theory related to the overarching question on experiences of fistula patients as they seek healing, from the point of recognition of the illness to their return to normal life. I used grounded theory to answer the following questions: 1) what key patterns of health seeking behaviour do women with obstetric fistula display in their quest for healing? 2) How do obstetric fistula patients cope with the illness? 3) What are the strategies that improve obstetric fistula patients' social reintegration? The broad answer which I will develop fully in this thesis is that women are often involved in complex health seeking pathways with the hospital as their key disperser - due to unmet needs - to alternative sources of care. Their reintegration after surgery is either fully or partially supported by key enabling factors. In

addition, there is a unique group of women who are able to start afresh elsewhere – integrate into new work and community environments away from the previous context in which the fistula illness occurred. I generated a theory grounded in the data represented in a conceptual framework that encompasses fistula patients' health seeking behaviour and reintegration after surgery and offers a clear understanding of the dynamic processes inherent in the holistic healing process.

1.4 Significance of the study

Why was this study necessary beyond fulfilling my academic objectives and professional training persuasion? The existence of obstetric fistula is both a public health problem and a matter of women's human rights to good reproductive health. The illness not only affects women's physical health but their mental and psychological and social wellbeing. Further, it interferes with their gender roles and is likely to affect their participation in development. The multifaceted nature of the illness requires multidisciplinary and holistic programs aimed at prevention, treatment and rehabilitation.

Often a midwife encounters and assists the woman who has had prolonged obstructed labour to deliver, often a stillbirth. As this study will demonstrate, the women may immediately or later on manifest with the classic symptoms of vaginal fistula, urinary and or faecal incontinence. At this point the women need corrective surgery, and are classified as cases of gynaecology and reproductive health nursing. But experts have shown that fistula is a collaborative obstetrics/ midwifery and gynaecology problem and should therefore be tackled in a continuum of care involving the two and other disciplines. In this thesis I will further my argument that beyond the basic surgical clinical and nursing care, there is chance for a more holistic approach to fistula care and offer a framework within which this may be done.

It is this holistic continuum of care that is so vital yet lacked sufficient scientific evidence on the how and why of the process that directed the inquiry in my research. What was known to us was purely clinical, before and after which we had no insight on the core substantive nature of the treatment seeking process or reintegration of patients. There was therefore need to investigate the problem using research methods that give an emic perspective on the problem and offer answers to the core question.

Qualitative methods of inquiry are likely to contribute immensely on the current debate on the health seeking behaviour and reintegration of fistula patients in Kenya, especially in women's experiences from the emic perspective. Specifically, understanding the health seeking behaviour patterns of women suffering obstetric fistula and reintegration after surgery has been deepened by the study, a gap in previous fistula research in the country. It is in the process of filling this knowledge gap that my research contributed to development of a model framework for reintegration of fistula patients. Thus, the study adds significantly to the existing scientific body of knowledge on obstetric fistula and provides information likely to influence advancement in public health policy and planning concerning reproductive health illnesses resulting from childbirth. Sufficiently, new information on health behaviour and reintegration of fistula patients has been generated and presented for maternal health and public health experts' use.

1.5 Study justification

Obstetric fistula is a condition that continues to cause suffering to women in Kenya, despite other nations in the developed world having eradicated it. Effort to ease patients suffering through surgical repair has gained momentum over the years in the country with good progress. However, more research was needed to comprehensively understand and cater for social and psychological needs of fistula patients. It is therefore necessary to establish what approaches

worked for better patient reintegration. Secondly, Understanding the behaviour patterns of women suffering obstetric fistula when they seek treatment was expected to generate useful information for shortening the time before surgery hence improve their condition. The research was expected to generate new knowledge for holistic management of fistula patients for their physical, social and psychological healing, an objective that was sufficiently achieved.

CHAPTER 2: LITERATURE REVIEW

The literature review chapter is divided into three sections. The first section describes background information on obstetric fistula. The second section examines literature with focus on the key concepts that were investigated in the study. The last section reviews relevant theoretical frameworks that were reviewed to arrive at the studies theoretical underpinnings, and how grounded theory was chosen as the most suitable research methodology that would generate substantive theory on the topic. A summary of all studies on the topic of obstetric fistula that were reviewed is attached in Appendix 11.

Narrative review approach to literature review

A narrative review was adopted for this literature review. A narrative review summarises different primary studies, making conclusions from it. Following the keys steps of a narrative review, the first step involved performing a preliminary search of literature to refine the topic. The second step involved identifying the articles relevant to my topic using the predefined search terms. The last step involved a synthesis of the results to make a conclusion.

Narrative review was chosen over other methods of review such as integrative or realist approach for the following reasons. First, the results of a narrative review are of a qualitative nature and are quite useful in understanding diversity and variations concerning a chosen topic (Green, Johnson and Adams, 2001). Secondly, narrative review offers a historical perspective of the problem of fistula and its management. Third, the approach is used to illuminate context thus provoking thoughts to a certain topic, as well as discussing theory (Green, Johnson and Adams, 2001). On the other hand, an integrative literature review is suited for new knowledge about a topic and the applicability of results to practice (Torraco, 2005; Souza,

Silva & Toracco, 2010). On the topic of health seeking behaviour for fistula patients, few studies were available for this type of review. A realist literature review would work well with a complex social intervention especially in program evaluation where the program theory is available (Pawson et al., 2005). There was no existent program theory in this study thus making the approach unfit for conducting the literature review. It is for these reasons that a narrative review was chosen for this study.

Search strategy

Search in peer reviewed journals and in grey literature for articles relevant to the study was conducted. Using the following search terms ‘obstetric fistula’ ‘vaginal fistula’ ‘health seeking behaviour’ ‘health behaviour’ ‘reintegration’ ‘social reintegration’ ‘coping’, 105 articles were retrieved online and 2 book chapters included in the review. Qualitative, quantitative and mixed methods articles were included for review, as well as review articles published on the topic. Besides the key concepts investigated in the study, the review also included papers that commented on qualitative methods and grounded theory methodology. All articles reviewed were restricted to English language, and articles older than 15 years were excluded from the review. The last condition was exempt for two classical works on stigma and chronic illness.

2.1 Background Information

Obstetric fistula is a condition where the vaginal canal communicates with the bladder resulting in incontinence of urine or between the vaginal canal and the rectum causing incontinence of faeces as a result of injury to the birth canal during childbirth (Gwyneth and Bernis, 2006). Globally an estimated 2 million women suffer obstetric fistula remaining untreated, and a further 50 000 to 100 000 new cases annually (Gwyneth and Bernis, 2006).

In Kenya, prevalence of obstetric fistula was estimated at 1 in every 1000 women in a facility based study conducted in early 2000s (Mabeya, 2004). A recent population based study report of the Kenya Demographic and Health Survey (KDHS) estimates that 1% of women in Kenya have experienced fistula (Kenya National Bureau of Statistics (KNBS) et al., 2015). This is a much higher prevalence than previously estimated by the initial hospital based survey. The KDHS key indicators report further established that women in North Eastern, Central and Nairobi regions reported slightly higher levels of fistula (2%) compared to other regions. In addition, women aged 30-34 years were more likely to have experienced fistula with the age specific prevalence at 2%. These two studies suggest a heavy burden of obstetric fistula disease in the country against a back drop of few cases being offered surgery every year. This means that the back log of fistula cases in Kenya may not be cleared soon. The prevalence may be higher than estimated because many women suffering from the condition remain hidden due to stigma, shame and disrespect resulting from the illness (WHO, 2005).

2.1.1 Contributing Factors to Obstetric Fistula

A majority of obstetric fistula cases in developing countries are a result of prolonged obstructed labour (Rochat, 2011). According to a World Health Organisation report, prolonged obstructed labour occurs in around 4.6% of pregnancies and causes around 8% of maternal mortality worldwide (WHO, 2005). It is important to understand that obstetric fistula is mainly caused by prolonged obstructed labour and thus possible sequelae in any of the pregnancies in which obstructed labour occurs. In addition, other symptoms of obstructed labour in addition to obstetric fistula may manifest.

However, there are other symptoms of obstructed labour that manifest alongside urinary and faecal incontinence. Thus, in keeping with the wide range of consequences of obstructed labour,

Arrowsmith and colleagues described an ‘obstructed labour injury complex’ that consists of symptoms such as foot drop, infertility and psychological trauma (Arrowsmith et al., 1996). The consequences of obstetric fistula surgery are presented in section 2.1.2.

Several factors contribute to the formation of obstetric fistula in developing countries (FIGO, 2006). The FIGO committee’s ethical guidelines on obstetric fistula identified several social, cultural and health system factors, namely, insufficient emergency obstetric care, lesser aged primi-parous women, female genital mutilation, gender discrimination, poverty, malnutrition, and poor health services (FIGO, 2006).

Socio-cultural factors contributing to obstetric fistula in Kenya include female genital mutilation that directly causes fibrosis and obstruction delaying second stage of labour, and indirectly through early marriage of girls after female genital mutilation resulting in adolescent pregnancy (Mabeya, 2004). Early marriages lead to pregnancy and childbirth at an early age when the girl’s pelvis is not yet fully developed. This may in turn contribute to cause obstructed labour due to cephalopelvic disproportion. Pregnancy at an early age is thus termed high risk and delivery ought to occur under skilled birth attendance with access to an Emergency Obstetric Care (EmOC) facility if referral is needed. In settings where skilled birth attendance is unavailable or inaccessible, obstructed labour may lead to formation of obstetric fistula.

The factors alluded to in Mabeya’s study are similarly reported, by Khisa and Nyamongo (2011). In a qualitative exploratory study, the authors explored perceptions of healthcare providers on the contributing factors to fistula in the region. They reported an interplay between sociocultural, structural and economic forces that contribute to formation of obstetric fistula namely female genital mutilation and ensuing early forced marriage; unskilled births attendance and associated

birth rituals; infrastructural challenges and lack of women's empowerment (Khisra and Nyamongo, 2011)

Even in the absence of FGM, women of any age can develop obstetric fistula. For instance, poor transport and infrastructure, unskilled birth attendance and lack of emergency obstetric care have been identified as generally contributing to formation of obstetric fistula (Cook et al., 2004b). Similarly, Mselle and colleagues demonstrated in a cross-sectional study of fistula patients in Tanzania that inadequate access to EmOC, poor transport, delay in decision making to seek care during labour and unskilled birth attendance contributed to severe birth injury (Mselle et al., 2011a). These factors interplayed to cause obstructed labour and delay to obtain emergency obstetric care hence formation of obstetric fistula.

Often, social factors interplay with health system factors in the formation of fistula. Concerning social factors, Donnay and Ramsey (2006) demonstrated that obstetric fistula affects women who are poor, young, married early and illiterate. Further, these women have little or no access to emergency obstetric care and mainly deliver at home with the of family members or traditional birth attendants as they are prevented from reaching good obstetric care in good time due to the three classic delays of delay in decision to seek obstetric care, delay in deciding which facility to go and the delay in making proper timely decision at the health facility level (Wall et al., 2005).

Developed countries have demonstrated that obstetric fistula can be eradicated by tackling the social, economic and systemic factors that increase the risk of obstetric fistula (Elneil, 2010, Wall et al., 2005). Specifically, universal access to essential obstetric care, emergency obstetric care and appropriate integrated social, economic and cultural development programs have been

recommended as a cost effective approach that rebuilds lives and may be highly sustainable (Mohammad, 2007, Elneil, 2010).

In conclusion, the contributing factors to obstetric fistula prevalence, basing on the literature here in presented include sociocultural factors such as early marriage, use of traditional birth attendants and home delivery, female genital mutilation, low levels of education and lack of women's empowerment, two of the three classic delays of decision to seek obstetric care in labour and delay in decision concerning the facility to visit. Infrastructural and health system factors include poor road transport, lack of access to emergency obstetric care facilities and the third of the three classic delays namely delay at the health facility level to make timely decisions in obstetric care. Often, an interplay in these factors results in formation of obstetric fistula.

2.1.2 Consequences of Obstetric Fistula

Obstetric fistula causes immense suffering, pain and disability to women. At the individual patient's level, obstetric fistula results into a number of consequences broadly categorised into physical illness, psychological illness and social and economic consequences. Physically, obstetric fistula causes incontinence thus continuous leaking of urine and / or faeces. However, there are other symptoms of obstructed labour that manifest alongside urinary and faecal incontinence (Arrowsmith et al., 1996). Thus, in keeping with the wide range of consequences of obstructed labour, Arrowsmith and colleagues described an 'obstructed labour injury complex' that consists of symptoms resulting from a pelvic 'field injury' namely incontinence, foot drop, infertility and psychological trauma (Arrowsmith et al., 1996). Other physical symptoms of untreated fistula include ulceration, infection, foot drop, dehydration and kidney diseases, (Rochat, 2011, FIGO, 2006).

In addition to physical symptoms, obstetric fistula causes ill psychological health. The psychological consequences of obstetric fistula are considerable, and often manifest as depression and early death from suicide in patients (FIGO, 2006). A study conducted in Kenyatta National Hospital in Kenya showed that 17.1% of fistula patients had suicidal ideation and depression was present in 72.9% of fistula patients (Khisa et al., 2011). Women may endure consequences of living with fistula even after reparative surgery (Khisa and Nyamongo, 2012).

Social consequences of obstetric fistula illness are widely reported in terms of the ensuing social stigma and isolation, mourning loss of the baby, and on the marital front, separation and divorce. Leaking of urine and the offensive smell makes women highly stigmatized and ashamed of themselves (Ahmed and Holtz, 2007, Cook et al., 2004b). Social stigma could further deteriorate the poor mental health of fistula patients and jeopardise their livelihood. They also face isolation, separation and abandonment by the spouse and family resulting in further decline in their economic status and collapse of social support systems. Ahmed and Holtz (2007) demonstrated that women suffering from fistula may be divorced and abandoned by their family, in addition to being rejected from their communities. Fistula is therefore considered a “social calamity” Ahmed and Holtz (2007). Similarly, in a study conducted in Malawi, women living with fistula reported experiences of seclusion and stigma owing to the offensive smell and cultural taboos (Yeakey et al., 2009,). Women who previously suffered from and were treated for obstetric fistula may find it difficult to reintegrate into their local communities, who often regard them as unclean or cursed. The stigma and isolation experienced during fistula illness may still be a challenge that lingers on even after corrective surgery (Yeakey et al., 2011, Khisa and Nyamongo, 2012).

Loss of social relations and associations is only a small aspect of loss that women with obstetric fistula experience as a whole. In a cross-sectional study in Tanzania, Mselle et al. (2011b)

demonstrated the extent of suffering that women living with fistula faced. The women described their experience of loss of body control at the physical level, inability to perform gender roles as women according to societal expectations of them as women and inability to integrate in social life with friends and peers. In addition, women reported loss of self-dignity due to having to depend on their family members economically, feelings of uselessness and self-contempt (Mselle et al., 2011b).

The consequences of obstetric fistula are therefore beyond physical symptoms of urine and faecal incontinence, to other related field injuries that result in nerve damage, infertility, and psychological trauma. The ensuing social stigma and isolation further secludes women and excludes them from leading normal lives. Beyond the women's physical health, their social status as women, being wives and mothers is jeopardised and they are likely to face divorce and separation. Economically, women who were already illiterate and of poor social and economic status sink further into poverty and depend on their family, losing their self - esteem and dignity. The consequences of living with obstetric fistula present as a public health problem, moving from being an obstetric complication to a reproductive health condition with wide range of effects on the individual and their family to nearly a quarter million women living with fistula in Kenya.

2.1.3 Obstetric fistula as a public health problem

Obstetric fistula is a public health problem whose eradication relies on disease prevention and health promotion, as well as improving the life of those who suffer it through treatment, rehabilitation and reintegration. However, obstetric fistula continues to cause suffering to 1% of women in Kenya with a recent study suggesting that the magnitude of the problem was previously underestimated (Kenya National Bureau of Statistics (KNBS) et al.). In addition to

the high prevalence as compared to other regions of the world who have eradicated the condition, there are other of reasons that situate obstetric fistula as a problem beyond obstetrics and gynaecology and midwifery. The little research attention previously accorded this problem, the lack of holistic approach to the care of fistula patients beyond repair, the heavy consequences on the patient and family all necessitate a broader look at the problem within a public health lens.

Indeed, that the problem of obstetric fistula was previously ignored until the last decade is evidenced in the dearth of published research on fistula care in Kenya. Most published work on the topic in Kenya has been on characteristics of patients and surgical outcomes (Mabeya, 2004, McFadden et al., 2011, Khisa et al., 2011). Other recent work has focused on contributing factors to the formation of fistula (Khisa and Nyamongo, 2011) and the community awareness of obstetric fistula illness (Omari et al., 2015). Recently, researchers focus on the period after surgery have used qualitative research to explore the plight of women after corrective surgery (Khisa and Nyamongo, 2012) and the reintegration needs of women after surgical treatment (Khisa, 2015).

Multinational health organisations like the World Health Organisation (WHO, 2005) and UNFPA in collaboration with the government (Ministry of Health Kenya and United Nations Fund for Population Activities, 2004) and nongovernmental organisations (African Medical and Research Foundation, 2011) have also contributed to the knowledge base regarding the topic of obstetric fistula in Kenya. Encouragingly, over time, the database of fistula research in Kenya has expanded significantly. However, the studies have focused on surgical outcomes and mental health of patients (McFadden et al., 2011). Few authors have spoken to the multidisciplinary approaches to treating fistula, or even paused to consider possibilities of success in such approaches.

Globally, other international authors have investigated the subject in Africa (Diallo, 2009, Arrowsmith et al., 2010, Wall, 2012a, Pope et al., 2011). Commonly, in these studies, the women's experiences are documented in terms of loss and surgical techniques that aid in treatment. Concepts of health seeking and reintegration are seldom featured in these articles.

Obstetric fistula causes physical, psychological and socioeconomic suffering to about 2 million women globally. Stigma and isolation becomes part of women's lives, the 'norm' (Yeakey et al., 2009). The burden of disease on women and family is enormous (Khisa et al., 2011, Yeakey et al., 2009, African Medical and Research Foundation, 2011). However, current attention to the problem is focused on curative services only, making it a neglected disease and a sign of violation of women's right to healthy reproductive lives (Cook et al., 2004b, Farmer, 2008b).

Women suffering obstetric fistula have survived from an obstetric near miss event and therefore have undergone a psychological traumatic event. Further to this, the women lose the baby who is either a stillbirth or to neonatal sepsis (McFadden et al., 2011, Khisa et al., 2011). In their communities, they experience social stigma and isolation further aggravating their mental ill health. Khisa et al. (2011) established, in a recent study amongst fistula patients in a repair camp in Kenya that patients are predisposed to high levels of depression with need for holistic management approach that includes mental healthcare and family support. In another study in a referral hospital in Kenya, McFadden et al. (2011) established that 8% of fistula patients experience depression post-surgical repair. These study findings further support the need for a carefully tailored reintegration program that caters for the contextual settings of the women, providing psychosocial support.

Several authors have pointed to the significance of obstetric fistula as a problem that perpetually affects women in the developing countries of Asia and Africa and in Kenya (Elneil, 2010, Cook et al., 2004b, Mabeya, 2004, African Medical and Research Foundation, 2011, WHO, 2010). Elneil (2010) stated that “obstetric fistula is a devastating complication of childbirth that often results in distressing physical and emotional symptoms for women.” McFadden et al. (2011) made explicit the challenges that women living with fistula face, namely physical, social and psychological problems. Often, the women are isolated and abandoned, living as outcasts especially when cultural beliefs attribute their condition to curses and evil spells. Such women may still face similar challenges after surgery. In a similar study Khisa et al. (2011) reported that women who are survivors of obstetric fistula tend to have psychological trauma and show signs of depression.

Health system factors namely poor essential and emergency obstetric care is a main contributor to obstetric fistula formation in developing countries. Cook et al. (2004b) point to the fact that developing regions of Sub - Saharan Africa and Southern Asia have lagged behind in eradicating obstetric fistula compared to developed countries due to poor health services, and calls for a human rights approach to eradicating fistula. Similarly, the United Nations (2010) report concluded that developed countries have reported significantly low maternal morbidity and mortality compared to the developing world (United Nations, 2010). Notably, women in the countries that have eliminated obstetric fistula have better access to essential and emergency obstetric care (EOC and EMOC). And this factor must be the first pillar of a human rights respecting health system. While resource constrains jeopardise this quest, at times all that is needed is a genuine prioritisation of women’s health in relation to their gender role of reproduction.

The evidence in the afore mentioned studies point to a problem that is a public health magnitude, in prevalence and the effects of living with the illness by individuals and their families. Further, the existing practice in Kenya does little to respond to the long term effects of obstetric fistula. In its current context, it is a women's problem, against a backdrop of families, communities and a nation that fails to give priority to gendered illnesses and provide holistic care. If lucky, a paltry 1201 get surgery each year and are left to their return to their communities and normal life through their own efforts. Do they eventually obtain normalcy? What is normal life to woman who has lived with fistula for a given period of time? These are some of the questions that are further interrogated, developed and presented in later sections of this thesis. The immediate need, however, is to examine the human rights aspects of living with obstetric fistula illness.

2.1.4 Human rights aspects of obstetric fistula

Obstetric fistula has attracted insufficient attention in the global and local resource allocation forums despite the immense physical, social and psychological suffering that women undergo. Similarly, many studies on obstetric fistula globally have focused on the period between surgical repair and healing; with surgical approaches getting the most attention. Like in the case of Kenya, establishing the prevalence of the illness was only achieved in the latest Kenya Demographic and Health Survey despite this survey being conducted every 4 years (Kenya National Bureau of Statistics (KNBS) et al., 2015).

Studies documenting the experiences of women living with obstetric fistula in Kenya are few (Ministry of Health Kenya and United Nations Fund for Population Activities, 2004). While the challenges the women face are documented, little is known on how patients seek to overcome these challenges, especially before surgical repair. A recent study in a hospital in western Kenya indicated that 35% of the women had experienced incontinence for one to five years and a

further 19% for over five years before treatment (McFadden et al., 2011). In a study in Uganda, Kabayambi et al. (2014) reported that often the obstetric fistula patients ability to cope with the illness is inadequate. Further, as demonstrated in the previous section, there is lack of specific approaches to social reintegration of patients who undergo surgical repair.

In an attempt to reposition fistula as an urgent public health concern on par with other illness and disease, (Wall, 2012b) compared the attention given to fistula versus common tropical diseases. The paper ‘Obstetric Fistula Is a “Neglected Tropical Disease”’ raises important issues that invite academic discussion on obstetric fistula as a public health problem (Wall, 2012b). They include prevalence of the condition, the problems that women living with fistula experience and the paradigm shift(s) necessary to address the problem. The author suggests a paradigmatic shift arguing that not only infectious pathogens in the tropics cause illness and suffering; there are other illness like fistula that affect the poor. A focus then should be on the neglected tropical *disorders* rather than the current focus on neglected tropical *diseases*, an approach which obscures the reality of other non-infectious illnesses in populations residing in the tropics. This obscurity is best witnessed in the resource allocation thus accorded in eradicating the different diseases both at the global and local level.

Globally, authors like Paul Farmer have situated the right to reproductive and other health within the human rights lens (Farmer, 2008b). Similarly, Cook et al. (2004b) outlined the human rights link of obstetric fistula emphasizing need for ‘equal’ obstetric care even in developing and resource poor settings.

A Human Rights Watch report of 2010 placed the problem of obstetric fistula within the human rights context in Kenya (Human Rights Watch, 2010). The lived experiences’ of women

suffering from obstetric fistula, from physical symptoms of incontinence, to stigma and isolation, and their inability to afford or in other cases not access specialized surgical treatment symbolize a certain system and infrastructural neglect. It validates a human's right approach that should ideally build on the basic rights of access to essential obstetric care and treatment of subsequent maternal morbidities to all women in the country instead of mere humanitarian approach (Wall, 2012b).

Why is lack of care for fistula patients a human rights violation? What rights are violated? Women ought not to live with permanent disability after obstetric near miss events, as suggested by the constitution of Kenya and the reproductive health policy that health and safe motherhood shall be guaranteed respectively. In adopting a human rights stance to the problem of obstetric fistula I pose an argument that it is as a reproductive health illness that impacts negatively on the right of women to healthy reproductive lives. Indeed, against the backdrop of reproductive health as human rights that the claim of obstetric fistula being '*a neglected tropical disorder*' has been made by Wall (2012b). For instance, Wall (2012b) emphasizes the authenticity and legitimate claim of the problem to the global public health debate, which often is obscured by big statistics and the '*overall epidemic picture*' at the expense of other '*meritous*' illnesses that affect the poor. By depicting the problems and suffering occasioned by the illness, there is sufficient factual evidence to back the call for resource mobilization towards preventing and treating the illness, albeit in a public health approach.

The notion of a human rights approach to women's reproductive health, whilst putting the plight of the women suffering obstetric fistula is plausible. Further, as demonstrated by prevalence and the dire physical, social and psychological consequences on women, obstetric fistula is indeed a not only midwifery and obstetric problem but significant to the wider public health realm. That

currently little attention is accorded the problem in the public care sector locally, demonstrates the grim reality of an illness devastating women's lives with scarce resources allocated and unresponsive policy. Tackling this public health problem using a humanitarian and human rights approach will not only heal the women currently living with illness but also ensure prevention of further occurrence of fistula illness.

2.2 Review of Key Concepts

There is a paucity of literature on health seeking behaviour of women suffering obstetric fistula and their subsequent reintegration into the community after surgery. A few authors have described women's experience in general and how they cope with fistula illness (Kabayambi et al., 2014). Others have focused on the patient's experience of loss during fistula illness (Mselle et al., 2011b). However, no study comprehensively describes women's therapeutic itineraries and their health seeking behaviours.

There still lingers the question, what possibly is a typical fistula patient's health seeking trajectory? How may this trajectory be modified to ensure better quality of life? What is the women's reintegration need? This section explores a review of the two concepts, 1) health seeking behaviour and 2) reintegration drawing examples from the fields of nursing, medical sociology and medical anthropology as applied to study other illness.

2.2.1 Health Seeking Behaviour

Women with fistula live with the condition for long periods of time before seeking help from the informal health sector. In the quest for healing, some consult traditional healers and formal health care workers, while some do not seek any help at all (Yeakey et al., 2009). Documenting these patterns of health seeking and possible explanation of their decisions could help strengthen

the health systems response to their needs in Kenya and other countries where women with fistula live in similar contexts.

Various studies document that fistula patients take a long time before presenting themselves for medical attention (McFadden et al., 2011, Yeakey et al., 2011). This trend is worrying as a patients' prognosis depends on, among other factors, the time taken before surgical intervention. Consequently, an in-depth understanding of the patterns of health seeking behaviour for fistula patients was necessary to inform design of interventions that shorten this period as well as overcome barriers these patients face whilst seeking treatment. Thus my study sought to document the experiences of patients from the point of illness recognition to when they are attended to at a formal healthcare system.

Ward et al. (1997) define Health Seeking Behaviour (HSB) as “an action undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy”. As such, health seeking behaviour (HSB) and health system response (HSR) are crucial concepts in eliminating disease (Hausmann-Muela et al., 2003). Thus, all activities undertaken by survivors to heal their illness contribute to further understand their challenges and afford them proper care.

Factors that compound HSB and HSR – social, cultural, economic and structure of health systems - also need to be considered when designing a fistula survivors' reintegration program. For instance, Olenja (2003) argued that health seeking behaviour is a result of the individuals decision making and further relies on household behaviour; community norms and expectations; health care provider characteristics and behaviours and context (cognitive, socio-cultural and economic).

It has been demonstrated in other illnesses such as malaria (Nyamongo, 2002), childhood diarrhoeal illnesses (Granich et al., 1999) and sexually transmitted diseases (Ward et al., 1997) that patients may seek remedy from various sources including folk medicine, informal healthcare systems and formal healthcare facilities. They may also use several of these sources at once. Good (1987) described patterns of healthcare seeking amongst Kenyan communities and concluded that patients utilise both biomedical and traditional medicine in their quest for healing, a condition he terms 'medical pluralism'. Therefore an in-depth understanding of the health seeking behaviour of fistula patients gives chance to proper intervention at the earliest point in time. Early treatment has been associated with better social and mental outcomes for fistula patients (Mohammad, 2007).

Community and individual level factors may influence an individual's health-seeking behaviour (MOH & UNFPA, 2004). In some cultures, the expectation for a woman to have the first baby at home is linked to proof of a true sense of womanhood and bravery. However, this expectation may result in prolonged obstructed labour (Mabeya, 2004). In West Pokot, for instance, the cultural expectation is that a woman should deliver in her husband's hut for the child to be legitimacy (MOH & UNFPA, 2004). Such cultural expectations negatively influence the health seeking behaviour of women in pregnancy and childbirth and are likely to manifest in the way women with obstetric fistula seek treatment.

Women with fistula face difficulty while seeking care from health care workers (Yeakey et al., 2011). In a study conducted by Yeakey and colleagues in Malawi, women suffering from obstetric fistula actively sought treatment from health centres, hospitals and traditional healers. Most of these women were frustrated due to multiple referrals, time and financial constraints which discouraged them from pursuing surgery. Further, the lack of understanding of the nature

of the condition and its causes delayed women from seeking treatment from formal health care system. In Malawi, some women elected not to participate in surgery due to fear of how they would be treated, or following negative persuasion from their communities (Yeakey et al., 2011). Others chose not to seek any help from formal nor informal health care providers. Furthermore, it may be that women within a social network may respond in a different manner to the condition than those who are completely ostracized.

Women with obstetric fistula often take years before they undergo corrective surgery. Infrastructural factors and cultural misperception of the condition are some of the key factors that have contributed to this delay (Yeakey et al., 2009), while other survivors may not have been aware that treatment for fistula exists (Gwyneth and Bernis, 2006). The health care system response to fistula survivors is varied (Elneil, 2010) with surgical approaches being given priority over counselling and psychosocial support for survivors. The condition attracts stigma, necessitates couple counselling and community mobilisation for reintegration. Further, it is recommended that the long term goal of any fistula repair program is to ensure access to skilled professionals for repair where the needs of survivors will be addressed with specialized, multidisciplinary and holistic approaches and subsequent reintegration of survivors (Gwyneth and Bernis, 2006).

From this review, there was a knowledge gap on the full range of health seeking behaviour patterns of fistula patients in Kenya which this thesis fills. Documenting the complete range of actors in the health seeking behaviour of fistula patients, and the factors that positively or negatively influence this health seeking is important in two fold. First, a complete understanding of their health behaviour will be documented in filling the knowledge gap. Secondly, this evidence will be important in improving the health of other fistula patients in the country.

2.2.2 Patient Coping

It is of interest to investigate how patients cope with the physical, social and psychological impact of living with obstetric fistula illness. For instance, social stigma is enacted by both survivors' family members and community members. However, most survivors have at least one person who supports them throughout their illness period. This suggests that the family plays an important role as a therapy management group and in the overall coping of fistula patients (Yeakey et al., 2009).

The families role in decision making during the patients quest for therapy is increasingly been recognised in various illnesses and especially illnesses involving the reproductive system. In a study of healing amongst communities in central and southern Africa, Janzen (1992) concludes that most communities possess their own “words, procedures and types of behaviours in interpreting affliction” (Janzen, 1992). In this study, Janzen demonstrates that family and community members play a key role in forming “social networks and therapeutic cell communities to perform what he terms as ‘discourses of healing’”.

Obstetric fistula illness affects the individual woman and her family as demonstrated in a study amongst fistula patients in Malawi (Yeakey et al., 2009). It is therefore of interest to explore the coping strategies that fistula patients employ to get by the effects of this illness as well as the role played by family members. The role of family on a patients coping with the illness and their subsequent quest for remedy is significant to the overall design of programmatic interventions targeting prevention of the condition, treatment and reintegration of fistula patients. In addition, the strategies patients employ in coping with illness may have an impact on their health seeking behaviour and subsequent healing process in recovery from obstetric fistula illness.

Individual coping mechanisms employed against fistula illness are seldom reported. For instance, to cope with fistula illness, women in Uganda used religious activities as a form of coping with challenges posed by the illness (Kabayambi et al., 2014). The authors report that the women applied both problem-based and emotion-based coping by hiding from public, observing strict hygiene, prayer, drinking lots of water and less food, use of polythene materials on top of clothes and ignoring people's comments. Authors note that the social coping measures were ineffective in dealing with obstetric fistula illness and recommended awareness creation, prevention and prompt treatment of obstetric fistula illness.

2.2.3 Reintegration

Fistula patients are often in a vulnerable and disadvantaged position socially owing to their condition. Following corrective surgery, obstetric fistula patients need counselling, social and economic support (Gwyneth and Bernis, 2006). Support for reintegration is important for women currently experiencing high levels of stigma, unsuccessful repairs, or stress incontinence after repair.

Women suffering obstetric fistula survive from an obstetric near miss event and therefore have undergone psychological traumatic event. Further to this, the women lose the baby who is either a stillbirth or to neonatal sepsis (McFadden et al., 2011, Khisa et al., 2011). In their communities, they experience social stigma and isolation further aggravating their mental ill health. Khisa et al. (2011) established in a recent study amongst fistula patients in a repair camp in Kenya that patients are predisposed to high levels of depression with need for wholistic management approach that includes mental healthcare and family support (Khisa *et al*, 2011). In another study, McFadden et al. (2011) found depression as one of the complications post-surgical repair for eight percent of fistula patients in a hospital in Kenya. The World Health Organisation has

acknowledged the role of counselling as an important component of care for fistula patients and their subsequent reintegration (Gwyneth and Bernis, 2006). Recent studies have highlighted the role of counselling in treating obstetric fistula patients. In current practice, general counselling sessions focus on abstinence for 3-6 months and delay of childbirth until two years postsurgical repair to allow adequate healing. Other organisations involved in care of fistula patients like Engender Health have developed a counselling tool with specific focus on family planning but without particular focus on resolving the depression that some patients may experience. This gap in care could account for the abandonment, separation and divorce amongst married couples. Counselling could also enhance cooperation with physicians' instructions by patients hence improving surgery outcomes. Overall, the role of counselling on reintegration of fistula patients is yet to be explored in Kenya.

It has been shown that an appropriate integrated social, economic and cultural reintegration program is a cost effective approach as it also rebuilds lives and may be highly sustainable (Mohammad, 2007, Elneil, 2010). Basing on a reintegration programme targeting fistula patients after surgery in Nigeria, Mohammad (2007) recommends that such programmes should be tailored to the specific needs of the women depending on their environment.

The need to tailor reintegration programmes to women's specific context is further emphasized by the WHO obstetric fistula guiding principles for clinical management and programme development (Gwyneth and Bernis, 2006).

The social context within which a fistula patient returns to after surgery is important (Diallo, 2009). In a project description of reintegration program for fistula patients that starts at the hospital into communities in guinea, the patients undergo physical and psychological therapy.

Thereafter, the women live with a host family in the community as a social immersion strategy after being discharged from hospital. (Diallo, 2009) reported improved self-esteem, confidence and emotional health for the women who participated in the social immersion strategy. The strategy also led to improved links between fistula repair facilities and the surrounding community in Guinea (Diallo, 2009).

Diallo (2009) describes a social immersion strategy used to reintegrate fistula patients following corrective surgery in Guinea. The program uses a host family to live with the woman after discharge. The woman and this host family then act as education and information agents to pass messages on fistula prevention and treatment.

From the reviewed literature, an integrated approach for reintegrating obstetric fistula patients involves interventions that can be categorised in three broad areas. Health worker interventions comprise of surgery and inpatient care, long term and couple counselling, family planning, infertility treatment, Antenatal Care (ANC) follow up and EOC in subsequent pregnancies, general sexual and reproductive health services. Social worker interventions comprise of follow up visits, community mobilisation and education on VVF prevention and treatment. Other multi-sectoral interventions comprise of economic support and skill or vocational training.

2.3 Theoretical Framework

This encompassed three topic areas of obstetric illness namely, illness, health seeking behaviour, healing and return to normalcy. A combination of theoretical frameworks were reviewed to identify the most relevant to guide the study. They are presented in this section in summary with critique on the strengths and weaknesses of each theoretical framework and their relevance to studying the health seeking behaviour and reintegration of fistula patients.

2.3.1 Health Seeking Behaviour Models

In general, Olenja (2003) describes two main categories of models of health seeking behaviour used in the medical context. These models are the determinants models and the pathways models. The determinants models focus on factors that aid or hinder patients from seeking healthcare services while on the other hand pathways models focus on the process and steps that patients follow when seeking health. Similar categories of health behaviour models are highlighted by MacKian (2005), who proposes a division of studies of health behaviour into two main categories based on their approach. The first category comprises studies which focus on the utilisation of the formal healthcare system, the health care seeking behaviour. The second category comprises of studies focusing on the process of illness response, the health seeking behaviour. McKian's categories are similar to Olenja's categorisation, in that determinants models are similar to those focusing on utilisation of health care, i.e. healthcare seeking behaviour models. The pathways models that focus on the illness response are similar to health seeking behaviour models. I present a review of models broadly categorised into determinants or health care utilisation models and health seeking behaviour models with its latest development, the pathways model.

2.3.1.1 Determinants Models

An example of determinants model is the four A's model emphasising on availability, accessibility, affordability and acceptability of health services as factors that enable or hinder maternal health (Thaddeus and Maine, 1994). In their classic review article 'too far to walk; maternal health in context' they outline the three classic delays of accessing maternal health services. They include delay in decision to seek obstetric care, delay in deciding which facility to go and the delay in making proper timely decision at the health facility level (Thaddeus and

Maine, 1994). Other examples of determinants models are the knowledge, attitudes and practices studies (KAP); Focused Ethnographic Studies (FES) and Rapid assessments (Hausmann-Muela et al., 2003). These models emphasise on the factors that enable or hinder patients from utilising healthcare services and may be categorised as healthcare seeking behaviour models (McKian, 2005).

Strengths of determinants model

The determinants model has several strengths that make it suitable to guide public health research. First, the determinants model helps health policy makers and service providers to make a quick and often quantitative evaluation of factors that improve accessibility of a certain health service. Secondly, the model is efficient in planning for the needs of the population as it enables identification of specific factors which may be modified to improve access of healthcare to patients.

Weaknesses of determinants model

The first weakness of determinants models is that they approach health and health care seeking behaviour as an end result, taking into account only factors that aid or hinder patients accessing health services. The model does not take cognisance of the process of health seeking and ignores other important factors like external influences on the individual, availability of folk medicine, traditional healers and other alternative home remedies. The second weakness of the model is its approach to health seeking behaviour from the healthcare providers' perspective with little input from the patient. The model lacks explanations as to why certain factors aid or hinder health seeking behaviour of certain populations, making it difficult to improve such services.

2.3.1.2 Health Seeking Behaviour Models

A critique of each health seeking behaviour model commonly applied in nursing, namely Health Belief Model, Theory of Planned Behaviour and Health Care Utilisation Model is offered below.

Health Belief Model

This model was originally advanced by Hochbaum in 1958 to help explain the failure of tuberculosis screening programs in the United States. The underlining concept of the health belief model is that health behaviour is determined by personal beliefs and perceptions about a disease. Figure 2.1 below illustrates the basic tenets of the health belief model.

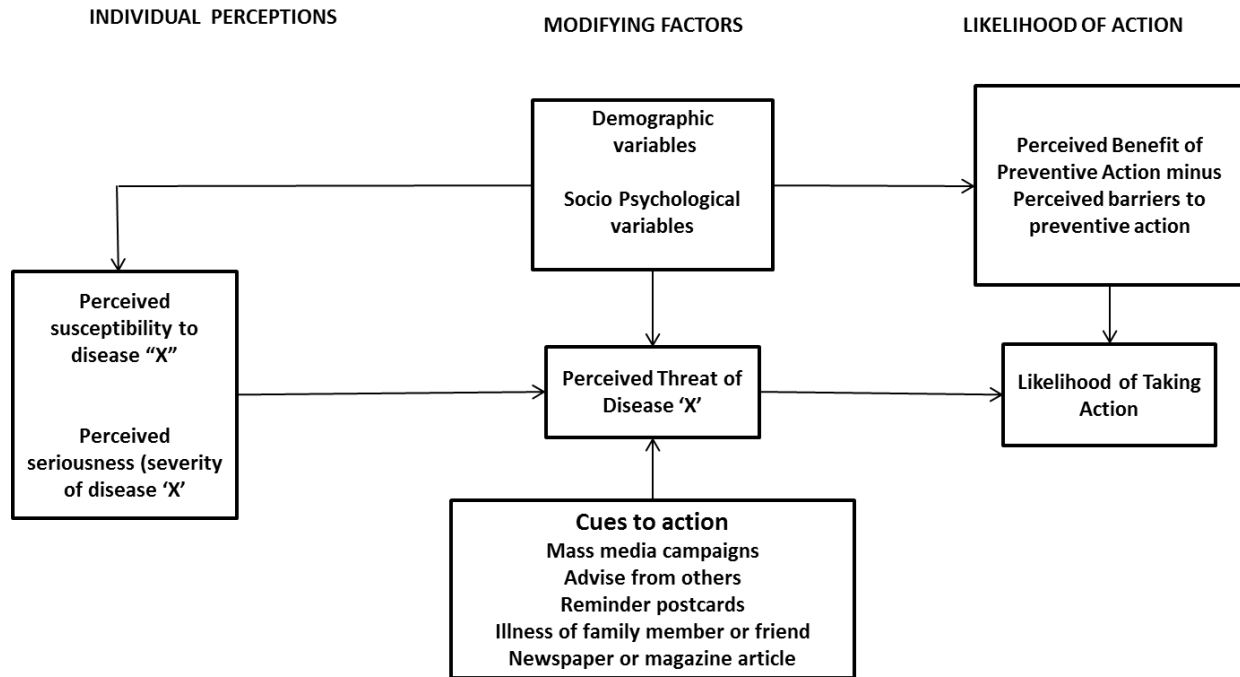


Figure 2.1: Health Belief Model by Hochbaum

The personal perception is further influenced by a range of intrapersonal factors affecting health behaviour. Perceived seriousness, susceptibility, benefits and barriers can be used to explain individual's health behaviour. Recent advancement included cues to action, motivating factors or

modifying variables and self-efficacy as important constructs that influence patients' perception, hence their health behaviour.

Theory of Planned Behaviour

Mostly used in public health, the theory of planned behaviour by Ajzen (2012) was derived from social psychology. The theory of planned behaviour is a development of the reasoned action theory (Ajzen, 1995). The theory has been developed further and used in various behavioural studies (Ajzen, 2012). In this model, behavioural intention is influenced by behavioural beliefs, normative beliefs and control beliefs that are then translated into intended then actual health behaviour. Figure 2.2 illustrates the expected effects of behavioural intervention in the theory of planned behaviour.

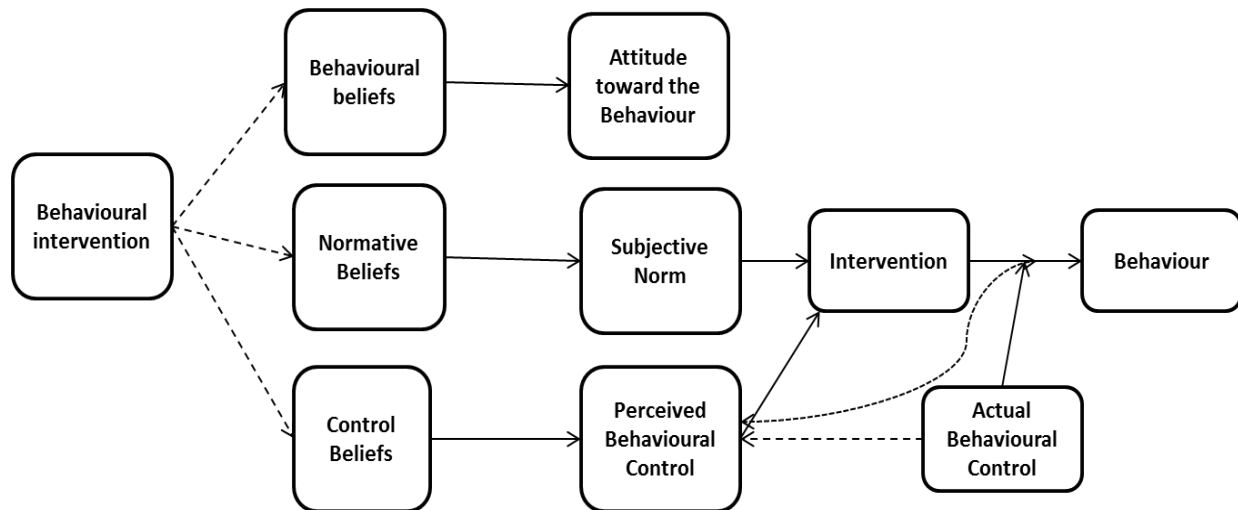


Figure 2.2: Expected effects of behavioural intervention in the theory of planned behaviour by Ajzen (1991)

Healthcare Utilisation Model

A model originating from medical sociology is the socio-behavioural model also known as healthcare utilisation model by Andersen (1995). Health care utilisation model is a socio-

behavioural model that proposes that environmental, predisposing and enabling factors, health system factors interplay to influence an individual's health seeking behaviour. The model depicts utilisation of health services as a dynamic process with with multiple influences and suggests that health outcome in turn affects the subsequent health behaviour of individuals. The model emphasises on an individual patient's utilisation of healthcare services as illustrated in Figure 2.3 below:

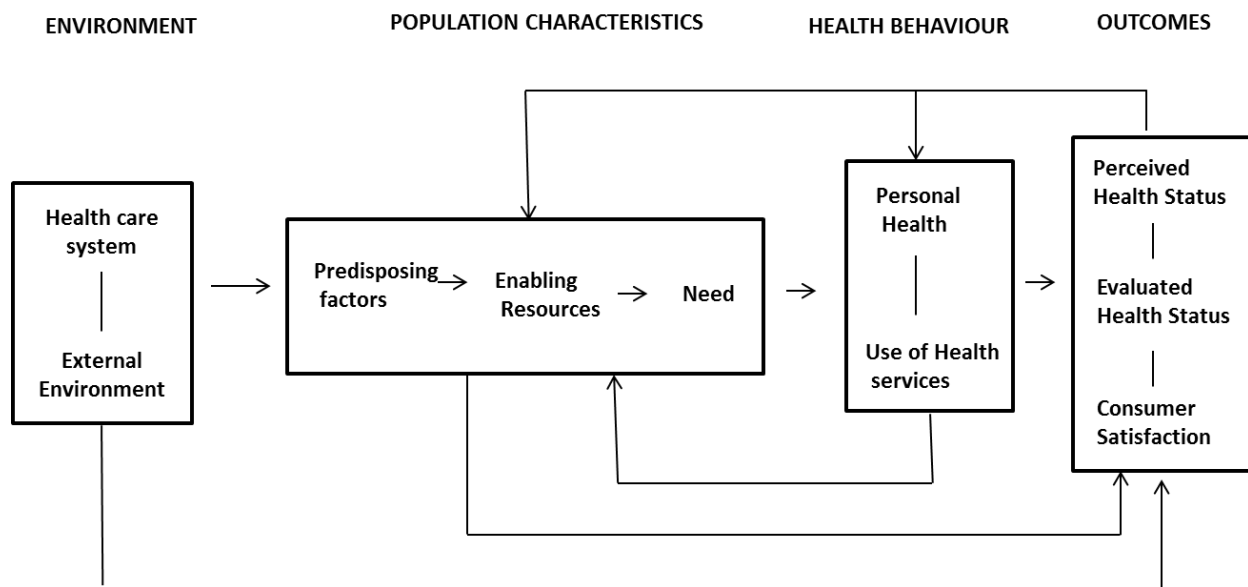


Figure 2.3: The Behavioural Model of Health Service Use by Anderson (1995)

The three health seeking behaviour models as used in nursing advance the logic proposed in the determinants models. The later models incorporate the patients' health beliefs, intended and actual behaviour. The models also recognise the contextual factors that may influence behaviour and likelihood of action. However, their disadvantage is that these models focus on formal healthcare utilisation only and fail to recognise the existence of other informal health care providers and their influence on the illness experience and the treatment seeking of patients. Secondly, the models fail to explicitly examine social processes like stigma and other temporal

factors as time lived with illness, aspects which are necessary in understanding obstetric fistula illness.

Although each of these frameworks addressed a certain concept relevant to my study, no single framework was found suitable to guide the study regarding the concept of reintegration. Grounded theory methodology was therefore identified as a methodology that would generate substantive theory with conceptual frameworks on the health seeking behaviour and reintegration of patients with obstetric fistula.

2.3.1.3 Pathways model of health seeking behaviour

Pathways health and treatment seeking behaviour models have their origins in social psychology, medical anthropology and medical sociology. Starting from the point of illness recognition, the pathways model enables a researcher to follow the various routes taken by the patient until healing occurs (Hausmann-Muela et al., 2003). The models present associations of variables that are considered applicable in explaining health-seeking behaviours. The pathways model guides researchers to obtain statistical data to evaluate relative weight of different factors such as choice between different health resources, consequences of behaviour for delayed health seeking and use of preventive or therapeutic measures to identify problematic areas and intervene using specific strategies.

Strengths of Pathways Model

Pathways models have numerous strong points which favour their utilisation. First, the models focus on the process that patients follow when seeking health, thus enables investigation on how this process may be lightened and shortened to help other patients with obstetric fistula. Secondly, the model takes a holistic approach to health seeking behaviour and takes into account

other factors that influence an individual's health. The models yield data that explains the reasons behind patients' decisions and action in seeking health, offering great opportunity to tackle such reasons in improving health.

Weaknesses of Pathways Models

A major weakness of the pathways model is that it requires in-depth investigation of the process of health seeking, hence may be time consuming and labour intensive. Similarly, the qualitative nature of inquiry in studies that utilise pathways models are cumbersome and often require advanced skill in qualitative research.

2.3.1.4 Pathways model utilised in this study

Considering the strengths and weakness of each theoretical model presented afore, I chose to utilise the pathways model to guide the investigation of the concept of health seeking behaviour of fistula patients. Patients of any illness often perceive the illness in varied ways. They may also vary in seeking help for their perceived health problems (Ajzen, 2012, Andersen, 1995). This notwithstanding, there is no known study of the health seeking behaviour of fistula patients globally. Whilst studies on health seeking behaviour of fistula patients in Kenya are scarce, the concept has been studied in other illness globally including malaria, childhood diarrhoea and sexually transmitted illnesses using the pathways model which I examine in this section.

The pathways model is a method of observing and recording the route a patient follows in seeking for treatment or remedy for an illness (Good, 1987). Often, the patients look back to narrate where, from who and what remedy they obtained for the illness. Figure 2.4 presents the original Good's pathways behaviour model:

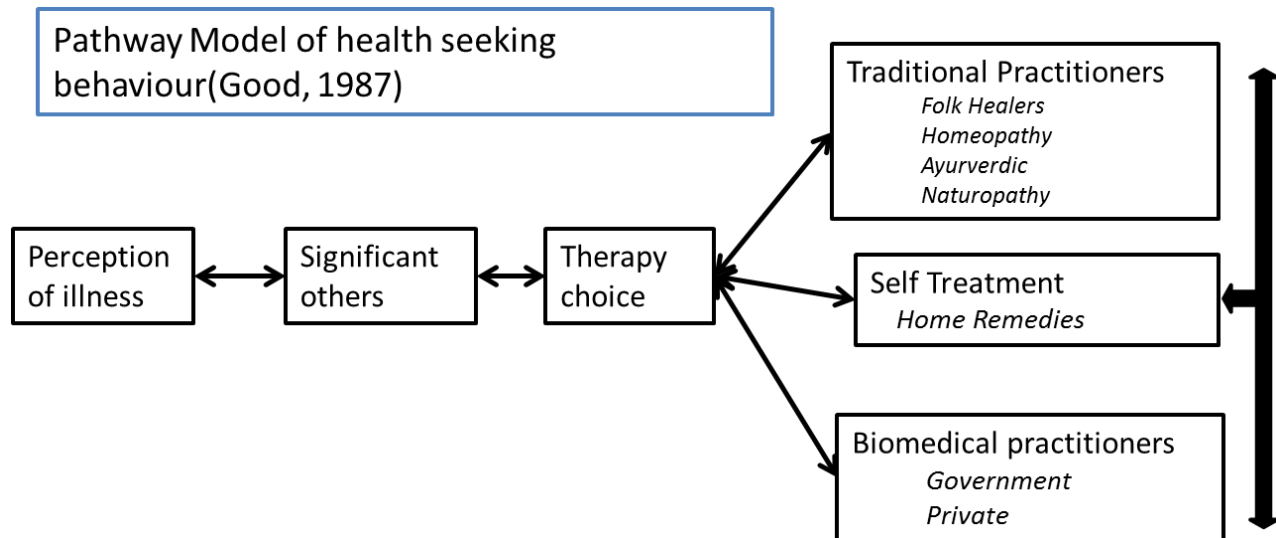


Figure 2.4: Good's pathways behaviour model

Pathways models of examining behaviour give more in-depth information about the phenomena under study (Nyamongo, 2002) as compared to knowledge, attitudes and practice studies, though the latter are easier to carry out (Hausmann-Muela et al., 2003). Other authors attest to the advantage of pathways models arguing that the model allows for thorough investigation of human behaviour, and caters for other factors that adduce to health seeking behaviour in addition to knowledge and attitude (Granich et al., 1999, Ward et al., 1997).

There is currently a long time period between when fistula occurs and the repair (McFadden et al., 2011). Hastened and positive health seeking behaviour patterns of obstetric fistula patients may lead to increased demand of repair services and better prognosis. Basing on the advantages, the pathways model is well suited to guide health seeking behaviour studies. The study was guided by the pathways model (Hausmann-Muela et al., 2003). Thus, patients' narratives on obstetric fistula were studied using a pathways model to map their health seeking behaviour patterns and therapy choices.

Basing on the review and critique, I chose to use pathways model to guide this study for three main reasons. First, research interest in health care seeking behaviour ought to address the complex nature of the process involved and take into considerations that any end result of health seeking behaviour is influenced by many other factors that interplay in an individual's quest for healing.

Secondly, the pathways model enables a researcher to investigate different paths followed by a fistula survivor from the time she recognises the symptoms to their use of different health services like home treatment, traditional healer or biomedical services. The assumption is that the health seeking behaviour is a dynamic process that is influenced by significant others in the decision making process and people other than the sick person act as therapy management groups. The model offered opportunity to unravel important insights on how the process may be modified to provide obstetric fistula patients holistic treatment.

Third, the pathways model has been used in numerous studies to predict health seeking behaviour with significant findings. For instance, Nyamongo (2002) used a pathways model to predict likely choices of therapy in malaria patients in Kenya. Similarly, the model has been used to predict health seeking patterns in diarrheal illness (Granich et al., 1999). For these practical, technical and methodological reasons, pathways model was therefore best suited to guide this study.

2.3.2 Theory of Culture Care Diversity and Universality

The nursing theory of culture care, diversity and universality advanced by Leininger (2002) is relevant to cultural aspects of the study and may be used to interpret the cultural value this research offers to the field of transcultural nursing. The concept of transcultural nursing was

coined to care for people of different and diverse cultural backgrounds thus development of the theory of culture care (Leininger, 2002). Leininger defined transcultural nursing as

“a substantive area of study and practice focused on comparative cultural care (caring) values, beliefs, and practices of individuals or groups of similar or different cultures with the goal of providing culture-specific and universal nursing care practices in promoting health or well-being or to help people to face unfavourable human conditions, illness, or death in culturally meaningful ways.” (Leininger, 2002)

The theory presents nursing as a learned profession with a disciplined focus on care phenomena. Care is defined as “to assist others with real or anticipated needs in an effort to improve a human condition of concern or to face death”. Caring is defined as “an action or activity directed towards providing care”.

Other nursing scholars have developed further the theory of culture care to meet the patient care needs, learner’s education and nursing research. Giger and Davidhizar (2002) developed a Transcultural Assessment Model to help in care of patients. The model includes six cultural phenomena: communication, time, space, social organization, environmental control, and biological variations. These provide a framework for patient assessment and from which culturally sensitive care can be designed. Glittenberg (2004) developed a transdisciplinary, transcultural model for health care and suggested ways in which such a model might be implemented, including a changed curriculum using on-line education, consultation, teaching, and research were the methods identified as possible ways of implementing the model.

Foronda (2008) further developed the concept of cultural sensitivity in transcultural nursing. Cultural sensitivity, a term used interchangeably for both cultural care and cultural competence,

has attributes of knowledge, consideration, understanding, respect, and tailoring Foronda (2008). Necessary antecedents to cultural sensitivity were identified as diversity, awareness, and an encounter. Foronda argues that an opportunity for these attributes and antecedents to interact would lead to the desired outcome of effective communication, effective intervention, and patient satisfaction. These three outcomes are the positive consequences of employing cultural sensitivity.

Other proponents of transcultural nursing have explored ways of conducting culturally safe research. For instance, McClelland (2011) discusses the research methodology appropriate for nursing research, suggesting qualitative methods of research are most suitable. Douglas et al. (2011) highlight updated standards of culturally competent nursing care. In recent years, the theory of culture care has been used to investigate diabetes (Whittemore, 2007) and maternal health conditions such as the uptake of caesarean section (Brown et al., 2010).

Proponents of the theory of culture care advocate for qualitative methods of data collection in research inquiries. Grounded theory is one such research method proposed to carry out research guided by the theory of culture care and diversity (Douglas and Pacquiao, 2010). Grounded theory is an approach that borrows heavily from anthropological methods of research to draw emic perspectives of care from clients. It therefore yields comprehensive rich qualitative data on phenomena being studied through use of narratives, focus group discussions and in-depth interviews (Bernard, 2005).

Relevance of theory of culture care to the study

The theory was relevant to and resonant to the study on the health seeking behaviour of fistula patients in the following instances. First, the theory assumptions are that each human culture has

folk remedies, professional knowledge, and professional care practices that vary. Such culture has both similarities and differences with other cultures in the world. Thus nurses must identify and address these factors for them to render holistic and culturally congruent care. Here, it is also assumed that cultural care values, beliefs, and practices are influenced by an individual client's worldview and language, as well as religious, spiritual, social, political, educational, economic, technological, ethno-historical and environmental factors. Thus, culturally beneficial nursing care can only occur when cultural care values, expressions, or patterns are known and used appropriately and knowingly by the nurse providing care.

Secondly, a study of patients' health seeking behaviour and reintegration patterns requires a theory of nursing that takes cognisance of the interaction and overlap of patients' culture, cognitive knowledge, folk medicine with professional practice; and the influence this interaction has on their ultimate health. In this regard, the theory offered potential to guide the investigation of the health seeking behaviour of fistula patients. Third, the theory proposes qualitative methods of data collection and grounded theory techniques of data analysis for an in-depth understanding of the problem under investigation. This study focussed on an in-depth understanding of the complete range of actions and actors in the process of health seeking by fistula patients; the experience of living and coping with fistula illness; and the ultimate process of reintegration of fistula patients. In these three instances, qualitative methods of inquiry were best suited to explore the problem as suggested by proponents of theory of culture care and universality.

These significant opportunities the theoretical framework offered, relevant to studying the topic were noted. However, it was deficient to use the theory to investigate the pathways of health behaviour as the theoretical framework offered no insight as to how this may have been done. Secondly, the participants in the study were drawn from different ethnic African groupings and

to attempt to negotiate what culturally competent meaningful care would be plausible to each participant would be difficult merely by the diversity of the background from which fistula patients originate. Moreover, culturally competent care is only one issue in the health behaviour of women, with other emerging issues needing a broader realm within which to interpret their narratives, for instance, time lived with illness and response to chronic illnesses and illness that attract social stigma and isolation. Finally, the reintegration experiences of women after fistula surgery could not be adequately interpreted within the transcultural nursing theoretical framework, since it is more oriented to the health seeking behaviour before treatment period. This led to the decision to use qualitative methodological approaches suggested by this model, since other studies on the after surgery period for fistula patients have affirmed its use as summarised in the following section. However, a more suitable framework to investigate the process of reintegrating fistula patients had to be identified.

2.4 Relevance of Grounded theory approach to obstetric fistula research

A review of literature on previous studies on obstetric fistula was conducted with a view to establish theoretical frameworks that could be applied in the study and interpretation of reintegration. Table 2.1 below presents reviewed studies on obstetric fistula post-surgical repair with an aim of identifying the theoretical framework that was used to guide the study.

Table 2.1: Theoretical frameworks used in obstetric fistula studies post-surgery

Author/Year/Ref	Title	Design, Method & Sample size	Focus Area	Reintegration issues explored	Theoretical framework
Ladeisha Lombard, Jorre, JS, Geddes, R El Ayadi, A Grant, Liz (2015) (Lombard et al., 2015)	Rehabilitation experiences after obstetric fistula repair: Systematic review of Qualitative studies	Systematic review (of primary qualitative studies) Using CASP N= 10 studies	Long term emotional, physical and social economic consequences of fistula; Return to normalcy	Gap between HCP and women's recommendations on reintegration that focus on community and social	None
Pope, Rachel Bangeser, Maggie Requejo, Jennifer Haus (2011) (Pope et al., 2011)	Restoring dignity: Social reintegration after obstetric fistula repair in Ukerewe, Tanzania	Both Quantitative and Qualitative methods N=71	Quality of life using PQOL and RNLI	Social interactions Economic activities/ work Time Residual incontinence	None
Maulet, N Keita, M Macq, J (2013) (Maulet et al., 2013)	Medico-social pathways of obstetric fistula patients in Mali and Niger: An 18 month cohort follow-up	Cohort study (Prospective follow-up) Mixed method but paper reported Quantitative only N=120	Fistula duration Patient Mobility No. of surgeries Care process duration Marital status Continence status	4 mobility patterns in the care trajectories of fistula patients in relation to patients continence status; "Quest for continence" does not end with reparative surgery Holistic customised care	None
Wilson, AL Chipeta, E Kalilani-Phiri, L Tauro, F Tsui, AO (2011) (Wilson et al., 2011)	Fertility and pregnancy outcomes among women with obstetric fistula in rural Malawi	Qualitative N=32	Conception and pregnancy outcomes after fistula surgery	Infertility Spontaneous abortion Perinatal death	None

Author/Year/Ref	Title	Design, Method & Sample size	Focus Area	Reintegration issues explored	Theoretical framework
Browning, A (2009) (Browning, 2009)	Pregnancy following obstetric fistula repair, the management of delivery	Short communication (Case series?) N=49 pregnancies (not patients)	Pregnancy outcomes	Return to reproductive capacity as return to normalcy Repeat vaginal fistulas if far from hospital during labour c/s as optimal care for birth ; recommend waiting areas in hospital	None
Wall, Lewis Arrowsmith, Steven (2007) (Wall and Arrowsmith, 2007)	The ‘continence gap’; A critical concept in obstetric fistula repair	Editorial commentary	Concept of successful fistula surgery	Continence Treating the whole individual - Psychological, sexual health, infertility, social reintegration	None
Turan JM Johnson, K Polan, ML (2007) (Turan et al., 2007)	Experiences of women seeking medical care for obstetric fistula in Eritrea: Implications for prevention, treatment and social reintegration	Qualitative interviews N=27	Interviews designed to generate information for community education and mobilization on safe motherhood To improve women’s medical and social services Follow up care	Both new and returning patients lacked awareness on the condition Reported improved patients conditions Post operatively, had residual incontinence and sexual health problems	None

There was a dearth of studies after fistula surgery to help understand the process of reintegration (Lombard et al., 2015, Maulet et al., 2013, Pope et al., 2011, Wilson et al., 2011). Further, no single theoretical framework for reintegration was identified by the studies as having guided the studies. The studies on fistula in the post-surgery period used qualitative methods of data collection and analysis to explain the post-surgical experience of women with obstetric fistula. However, the authors did not present any theoretical frameworks that were used to guide their research besides using qualitative methods to study experiences of women. This contributed to my choice to use qualitative methods that would allow theoretical framework development to fill this academic and knowledge gap in care of fistula patients in Kenya.

The topic of reintegration has been studied in other topics of public health. For instance, Boothby, Crawford and Halperin (2006) used qualitative methods to investigate child soldier life outcomes in Mozambique. The focus of their study is on the physical, psychological, social and economic functioning of individuals who had been previous child soldiers. Similarly, (McKay, 2004) focuses on physical and psychosocial aspects of reintegration for girls after civil wars in Sierra Leone and Uganda. Though these two studies focus on the topical area of civil war, they resonate closely with studies that have focused on reintegration and rehabilitation after brain injury (Karlovitz and Mccoll, 1999).

The common thread from studies on reintegration, both on fistula research and other public health topics lies in their focus on the individual's physical, psychological, social and economic return to normalcy; and use qualitative methods of inquiry as standalone or as combined with quantitative methods.

2.5 Methodological approaches

Several authors describe qualitative methods and grounded theory methodology as used in varied disciplines of transcultural nursing (Dunne, 2010, Guest et al., 2006); and

anthropology (Bernard, 2006) and (Ryan and Bernard, 2003). Specifically, Bernard (2006) description of sampling for grounded theory techniques was applied in this study. Similarly, the description of Ryan and Bernard (2003) on how to identify themes in thematic data analysis was applied. In-depth interviews and sample size calculation in qualitative research have been addressed succinctly by (Guest et al., 2006). Further, Dunne (2010) explains the place of the literature review in grounded theory approaches. The author argues that in grounded theory research, literature review is conducted as a final step in testing fit of the developed theory emergent from data or conceptual framework and further refining the theory (Dunne, 2010).

Ultimately, there are several challenges that a researcher applying qualitative research methods such as in-depth interviews and narratives may face. First, the method is labour intensive and requires a keen interest in the subject under study (Bernard, 2006 2005a, Creswell, 1998); secondly, identifying themes and vignettes in coding the data can be time consuming and need several attempts, as well as the data analysis (Bernard, 2006). Lastly, the delicate nature of conducting research on sensitive topics such as sexual and reproductive health is challenging, and (Bernard, 2006) and offer useful insight and examples on how to navigate the challenges. Despite these shortcomings, qualitative research is beneficial because it provides varied categories of analysis and has greater implications for understanding the complexity of women's experiences, since most categories are not independent and isolated. For instance, in this study, a jeopardised marital status overlaps with (in) fertility issues and gender role insufficiency in the complex problem of obstetric fistula. This complexity is best reflected in the women's explanation of their experience living with and being treated for fistula in qualitative research.

Furthermore, both qualitative and quantitative approaches are useful in exploring the impact of illness on women's health. They both reaffirm the need for a comprehensive and multi-disciplinary response. For instance, Khisa et al. (2011) and Yeakey et al. (2009) used different approaches of inquiry to explore the impact of the illness on women's lives. Khisa et al. (2011) used a cross sectional design to study patients attending a fistula camp with focus on their mental health. The study established that women with obstetric fistula are predisposed to depression and recommend inclusion of mental healthcare and family support in patients' management. On the other hand, (Yeakey et al., 2009) used a phenomenology theoretical perspective in investigating the lived experience of Malawian women with obstetric fistula in a home setting. The qualitative study focused on various aspects of obstetric fistula: the physical, psychological and triangulated data sources from women living with fistula and their spouses, mothers and sisters. The study concluded that women had varied experiences and were concerned with their marital relationships, fertility, stigma and fulfilment of their gender roles as women. They also reported high levels of support from family and individuals close to them. Despite using different methods, both authors agreed that programs should focus on a broadened range of outcomes and holistic approach to treating women with obstetric fistula. They situate the problem within a public health sphere and report on the quality of life of women suffering obstetric fistula.

In the absence of a single most inclusive and representative theoretical framework to guide the research on the health seeking behaviour and reintegration of patients with obstetric fistula, there was need to settle on a methodological approach that is inductive and generates midlevel substantive theory as its end goal. In addition, qualitative methods of inquiry were most suited to investigate the reintegration process. These two main factors led to the choice of grounded theory techniques.

Chapter three describes in detail how grounded theory methodology was used to generate substantive theory on healing obstetric fistula illness, and return to normalcy. Basing on these grounded theory methodological approaches, the study was conducted in three fistula repair centres in Kenya.

CHAPTER 3: METHODOLOGY

The methodology chapter is divided into nine sections. The first section provides background information on the hospital study sites and community follow-up. The second section presents a description of grounded theory methodology as qualitative research design with unique steps and procedures. This section describes the paradigmatic stance which led to the chosen methodology, including the ontological and epistemological positions.

The third section describes the study population and inclusion criteria, followed by the steps in purposive sampling of participants in the fourth section. The fifth section describes the methods of data collection that were used. The sixth section focuses on data management, coding and analysis in NVIVO, further expounding on grounded theory techniques of data analysis. The last two sections describe how quality assurance was obtained in the study and the various ethical considerations and permissions that were obtained to conduct the study.

3.1 Study area

The initial recruitment of fistula patients was conducted in hospitals. Fistula being a stigmatised condition, it would be difficult to identify women to interview before the surgery. Moreover, there was no guarantee that if such women were found in the community, they would undergo free surgery, and therefore conducting follow up for reintegration after surgery was not certain. These two main reasons made the choice of recruiting women in hospital immediately after surgery as the best in terms of accessing the participants and examining the health seeking behaviour and consequently the healing and reintegration process.

The study was conducted in three VVF repair centres in Kenya, namely Kenyatta National Hospital (KNH), Gynocare Fistula Centre and Kisii Level 5 Hospital. At the time of

recruitment in the year 2013, these hospitals carried out free fistula repair surgeries in the country. A fourth potential study site, Moi Teaching and Referral Hospital did not conduct free fistula repair surgeries in that year and was consequently replaced with Gynocare Fistula Centre located in the same region.

KNH is a national referral and teaching hospital located in Nairobi. The KNH complex hosts the University of Nairobi's College of Health Sciences, the Kenya Medical Training College, Kenya Medical Research Institute and National Laboratory Service. KNH has 50 wards, 22 out-patient clinics, 24 theatres (16 specialised) and Accident & Emergency Department with a total bed capacity of 1800. The hospital has a vesicovaginal fistula clinic that is run in partnership with Africa Medical and Research Foundation (African Medical and Research Foundation). AMREF is the main organization offering surgical treatment for fistula patients in East Africa. During each year, AMREF conducts fistula camps where patients receive free treatment at KNH.

Gynocare fistula centre is located in Eldoret town. It is a non-governmental healthcare institution registered with the NGO Coordination Bureau in 2011 with a bed capacity of 20. The centre conducts free fistula surgeries to the public with the support of One by One Fistula Foundation and Freedom from Fistula Foundation. The hospital has a dedicated theatre that conducts about 25 VVF surgeries each month totalling about 300 surgeries a year.

Kisii level 5 is a district hospital operational in Kisii County with a capacity of 379 beds. The hospital collaborates with visiting surgeons to conduct fistula repair clinics/ camps annually. Kisii level 5 has an existing partnership with AMREF for treatment of women with fistula. Approximately 60 surgeries are performed during such camps. The hospital also trains health care providers in care of fistula patients.

Study context

The environment in fistula care in 2013 and the preceding few years was that of increased surgery and awareness to the public about fistula illness. Announcements on national radio about obstetric fistula were aired especially a few months prior to the free medical camps at Kenyatta National Hospital. There were also advertisements made by Gynocare fistula centre in addition to their ongoing regional representative meetings in the community forums. Since the early 2000s, there has been NGO and government facility and healthcare provider partnerships towards fistula care.

This heightened awareness around fistula is expected to have impacted the level of awareness of surgery as an available treatment to the patients, and general awareness of community members about existence of such illness. As such, women who attended the free medical camps heard the announcements directly or were informed by a friend who had. It is possible that this influenced the treatment seeking pathway of the participants as well as community members' interaction with them. The initial recruitment and interviewing of patients took place in the three hospitals. The community follow up interviews occurred in their homes.

Community follow-up sites and theoretical sampling

The initial follow up interviews were held with women residing in the rural areas. However, there was need to compare their reintegration with data from women who resided in urban areas. Other theoretical sampling considerations were along women's education levels. For instance, the initial sample of women included those with college level of education but later proved to be a fewer to come across. Some women were at the two extremities of age, from adolescence, reproductive age to postmenopausal women. We recruited those who had lived with illness for long periods of time and those who had a short period of illness, all included as a source of comparison for deviant cases. Finally,

the study included both women who had children and those without any surviving children. The study population presented here allow for all possible extreme variations in characteristics of a fistula patient in Kenya.

Figure 3.1 shows a map of the geographical location of participants during community follow-up. The women who were followed up in the community for reintegration are represented in the map with yellow GPS points. A limitation to this map is that participants residing in the Nairobi peri-urban area could not be mapped since we had no GPS machine at the time of community interview, presenting a limitation to our methods.

3.2 Study Design

This was a grounded theory study. The study aimed at generating theory on the health seeking behaviour of patients with fistula illness and how they regain normal lives after reparative surgery. The choice of grounded theory was influenced by the critical realism paradigm, as described in section 3.2.1.

3.2.1 Paradigmatic Stance

It is important to state the paradigmatic stance that I adopted in this study, in order to understand the subsequent methodology that I chose in conducting the study. From an ontological perspective, I adopted the critical realism ontological stance (Scott, 2005). I approached this study with a world view that other things exist, seen or unseen. In addition, reality depends on individuals' views and these views could vary amongst individuals. For instance, the reality of healing for a fistula patient could vary, even when they had undergone the same treatment. An individual patient's narrative would therefore represent the reality of her world, in her own world view that is yet seen or known by

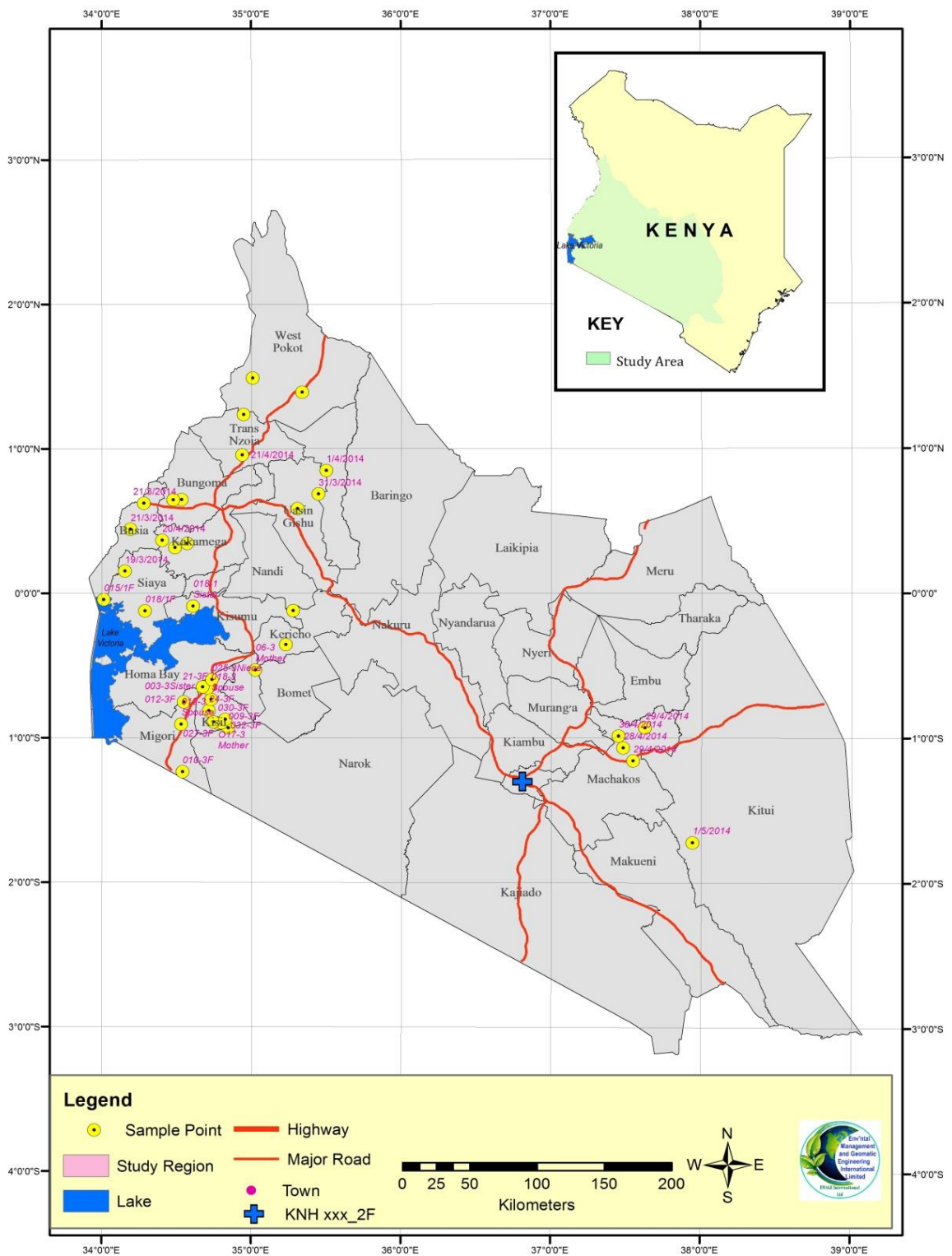


Figure 3.1: Map of the community follow-up for the reintroduction of fistula patients study

others, including medical experts. I thus inclined towards the idea that a holistic reality, summing up the patients experiences and their interaction with communities was more informative than the separate parts of her treatment and healing.

Concerning my belief around how knowledge is obtained, I adopted the epistemological stance that knowledge is relative. Knowledge therefore depends on both epic and emic perspectives; thus interviewing both family and health care providers and the patients themselves. In this case then, patients were considered experts in their own illnesses, thus the decision to anchor the research on patients' narratives of their own experience. I also was of the persuasion that knowledge about one single subject can be owned by different disciplines. In this case, the ideas of lay people represented by family members and patients was obtained and laid side by side with expert health care providers represented by social workers, clinical officers, nurses and counsellors. The other epistemological stance I adopted was the belief that knowledge keeps changing, and thus at different phases conducted multiple interviews with the same participant. Lastly, I was persuaded that facts are proven thoughts and other unproven thoughts could still exist, which then meant that at any point in time, not all was yet known about the behaviour of obstetric fistula patients, nor their reintegration outcomes. Until these patients unproven thoughts were obtained, we would remain with only a part of the knowledge.

These ontological and epistemological stances informed my methodology of acquiring knowledge on the topic of obstetric fistula thus. I was of the school of thought that the production of knowledge collectively should be all inclusive i.e. involve both lay and expert; nurse and patient; hospital and community; social and biomedical. Knowledge is not produced but rather collated from these different sources. I therefor chose grounded theory methodology that would help me execute collation of knowledge. Secondly, the methodology of producing knowledge should be continuous as opposed to one time

incident. Thus, the study moved from phase to phase as one collective process made of parts, thus viewing the entire experience of patients with the illness.

Finally, in reflecting on the pedagogy of knowledge, I was persuaded that individual knowledge production should be spontaneous; guided only by the broad goal but flexible enough to allow new thoughts and ideas and that there is no place for hard stances in pedagogy. I thus chose a methodology that would emerge new ideas about obstetric fistula in Kenya, grounded theory that is further expounded on in the next section.

3.2.2 Grounded Theory Methodology

Grounded theory methodology is a research design that uses qualitative methods of data collection and analysis to generate inductive theory based on the data obtained, about a certain topical issue representing human interactions (Bernard, 2005). Grounded theory methodology is not a theory but rather a methodological approach to generate substantive theory from data that was developed by Glaser and Anselm Strauss in 1967 for the purpose of building theory from data (Strauss and Corbin, 1990). The Glaserian grounded theory has been modified by Strauss and Corbin in recent times (Strauss and Corbin, 1998) and Charmaz (2002). Charmaz emphasized a constructivism approach to the method, moving away from the ‘grounding’ in the data concept that was the hallmark of the glaserian grounded theory (Charmaz, 2002, Charmaz, 2006). This study applied the Strauss and Corbin (1998) grounded theory methodology, adopting a critical realist world view to the way knowledge is acquired.

The two phased study used narrative guides and in-depth interviews to collect data (Guest et al., 2006). Data analysis based on grounded theory techniques was used to analyse qualitative data. Three stages of coding as described by Corbin and Strauss (1998), namely open, axial and selective coding were applied. Theoretical sampling, writing

memos and reflexivity were applied and are discussed throughout the methodology and results section of this thesis.

The study thus involved recruitment and follow up of patients in the community after surgery. The first narrative interviews were conducted with women who had fistula surgery immediately in the recovery period before discharge from hospital. Subsequently, I conducted either one community based narrative at 9 months after surgery or two interviews at 6 months and 12 months for comparison along time, totalling three interviews per woman. Section 3.7 describes the steps that led to decisions on repeated measurement and constant comparison.

The study was carried out in two main phases, recruitment and follow up. However, data collection and analysis was carried out concurrently throughout the study to inform further sampling and analysis. Thus, the recruitment at site three sampling was largely informed by analysis of data from site one. However, for clarity, it is suffice to present the two phases separately.

The recruitment Phase I was carried out during participants' inpatient stay after surgery. This stage documented health seeking behaviour patterns of fistula patients and their coping mechanisms. At this phase, participants were explained to about the study, its objectives, and their roles, including the long term nature of the study and the follow up visits and interviews that would be conducted in their homes. A consent information sheet in Kiswahili language was used. Upon agreement to participate, participants were requested to sign an informed consent form by signature or thumbprint, a copy of which they retained. Appendix 2 is a copy of the informed consent forms that were used in the study. A narrative guide was used to investigate the patients' health seeking behaviour patterns from the point of illness recognition to their first contact with the formal health care system. Demographic data was obtained using a patients' demographic profile at the

end of the interview. A separate form was used to obtain information on name, home location and contacts of the patient for purposes of follow up phase of the study. The form was handwritten, never copied nor typed and was kept locked separately from the rest of the data to ensure complete anonymity of the participants' identity. It is presented in Appendix 8.

Phase II comprised follow up of patients at six to nine and at twelve months after discharge from hospital to assess their reintegration into the community. Locating the study participants during follow up depended on their availability and willingness to participate as agreed in the initial informed consent process. They were contacted using the address provided during recruitment and with the help of community health workers in the patient's home region. The interviews were held with participants in their home settings focusing on the extent to which they had resumed normal lives after surgery and the support they had received that was aimed aiding their reintegration.

Rationale for grounded theory approach

Grounded theory methodology was used to generate theory on the entire wellness seeking trajectory of fistula patients, to healing and ultimate return to normalcy. Grounded theory approach was applied because it allows emergent theory based on data that represents fistula patients' reality. Moreover, in an exploratory manner, the method allows collation of new, inclusive and context specific data which is a true reflection of the women's life realities.

Lastly, the method enables the participant to co-create knowledge with the researcher, thus becoming a key informant to how fistula care should be tailored. The resultant framework is based on the premise that the women after fistula surgery should not only be mere

recipients of outwardly crafted theoretical and practical interventions but be at the core of the process of generating such rich data as grounded theory methods permit.

In this thesis, the use of grounded theory has generated rich, in-depth and nuanced accounts, opinion and suggestions of women who have suffered from fistula. The narratives walk the reader through what it means to live with and endure fistula illness, and the recovery and return to normalcy process, focusing as it does on issues core to the patient's experiences.

Rationale for Corbin and Strauss approach to GT

It is important to note that the study applied grounded theory as proposed by Strauss and Corbin (1998), and not the classic grounded theory that was earlier proposed by Glaser and Strauss nor the most recent constructivist grounded theory as proposed by Charmaz (2006). Decision to follow the Corbin and Strauss (1998) approach to grounded theory was informed by three factors. First, this method was in keeping with the paradigmatic stance which I adopted in this study. Secondly, the constructivism suggested by Charmaz (2006) would take away the emic perspective and push the research towards the epic, for which data from numerous studies were already available. Third, classic Glaserian grounded theory requires a most flexible approach to the design of the study, including use of an opening broad question and evolving other questions as the interviews progress. Further, strictly data had to be analysed before more data was collated, the nature of which would be determined by previously obtained data. This level of flexibility would not be permitted by the current ethical committee requirements, and the limited time within which the research had to be conducted.

Grounded theory approach has unique steps and procedures (Strauss and Corbin, 1998). They included, as achieved in this study, analysing data in three main iterative and

overlapping steps of open, axial and selective coding. Open coding is a process of coding data towards saturation where one discovers new categories (codes) and defines their properties, whilst constantly comparing data to data and category to category. The stage also entails writing memos of what is happening in the data, an initial interpretation of data. Axial coding explores relationships of categories (codes) to each other, exploring the central idea around the phenomena, causal conditions of the phenomena and context. This second step may generate a theoretical model. Selective coding identifies a single category as a central phenomenon then constructs around it a story line.

3.2.3 Potential approaches that could have been used

The study of patients' experiences can be obtained using qualitative approaches other than grounded theory methodology. Phenomenology is one such method that can effectively investigate the lived experiences of patients (Hennink, Hutter & Bailey, 2011). The method is rigorous and can obtain rich data on topic of inquiry. However, two main factors limited the use phenomenology in this study. First, it explores experiences rather than processes, and was therefore insufficient to investigate the process of healing and health seeking. Secondly, theory generation is not the end aim of this methodology.

Another possible qualitative approach that can be used to investigate obstetric fistula is ethnography (Hennink, Hutter & Bailey, 2011). This method offers an indepth and complete understanding of phenomena, especially in the naturalistic setting of the participant (Bernard, 2006). In this study, conducting ethnography would require the researcher's constant and continued presence in the participant's home for a minimum of six months. This raised challenges in terms of limited time and finance within which PhD research is expected to be completed. A variant of ethnography, hospital ethnography would not afford the researcher opportunity to conduct community follow up interviews, where reintegration is expected to occur.

Grounded theory on the other hand is suited to examine people's experiences and processes (Bernard, 2006). The method was less time consuming compared to ethnography and more flexible to investigate a full range of varied descriptions of the phenomena. Finally, in the absence of a suitable theoretical framework, the methodology allowed for generation of a mid-level theory of regaining normalcy for fistula patients (Bernard, 2006).

3.3 Study population

The study population comprised of all obstetric fistula patients in VVF repair centres situated at Kenyatta National Hospital, Kisii Level 5 Hospital, and Gynocare Fistula Centre.

Inclusion criteria

Target population

The target population comprised of select obstetric fistula patients in VVF repair centres situated at Kenyatta National Hospital, Kisii Level 5 Hospital and Gynocare Fistula Centre.

Inclusion criteria

Patients from the selected VVF centres were recruited into the study if they met the following criteria:

- i. Patients with a vesicovaginal or rectovaginal fistula diagnosis.
- ii. Patients with a VVF/ RVF caused by labour and childbirth.
- iii. VVF/ RVF patients who had undergone corrective surgery

Exclusion criteria:

- i. Women who suffered urinary and /or faecal incontinence caused by other processes than labour and childbirth.
- ii. Women diagnosed with obstetric fistula who had not undergone corrective surgery

Recruitment Procedure

To avoid double participant recruitment careful screening of potential participants before final recruitment into the study will be done. Following informed consent, potential study participants will be subjected to a screening to rule out whether they have been recruited in this study before and whether they have been referred to the current treatment centre from another hospital that is a participating site to this study.

The participant will be given a unique identifying number and they will be asked to remind other interviewers about their participation in this study. A database of those recruited before was developed as the study progressed, making it easier to eliminate chances of double recruitment by cross checking with the information in the participant follow-up index. An up to date database was availed to the research assistants.

3.4 Sampling

Purposive sampling was used to recruit participants at three fistula repair centres in Kenya using the criterion described above. The criteria for purposive sampling was thus for patients from the selected VVF centres patients who had undergone corrective VVF/ RVF surgery, and those whose VVF/RVF was caused by labour and childbirth. Women who suffered urinary and /or faecal incontinence caused by other processes than labour and childbirth were excluded from the study.

The systematic nature of grounded theory requires that data is analysed before more data is collected. This was first done in Gynocare which carries surgeries throughout the year. Data Saturation for themes on health seeking behaviour in narratives from Gynocare was reached at 30 and an additional 5 to cater for 'loss to follow up' that would be expected to occur in a 1 year follow up study as this.

There was however need for a flexible approach to sampling due to the rapid nature of free fistula repair camps. At most, camps were held for a week in Kisii and Kenyatta hospitals respectively. This meant analysing one participant's narrative before recruiting the next would not be possible for the two sites. Taking a cue from the first sight, it would be sufficient to recruit 30 participants, given they were from one county and therefore homogeneous. Thirty five participants who satisfied criteria were therefore recruited in a week's camp at Kisii hospital, a similar number to Gynocare. Kenyatta national hospital presented opportunity to recruit women from diverse backgrounds and characteristics and 48 were recruited, totalling 121 at phase 1. Data collection for phase one was conducted between May 2013 and October 2013.

The sample size was mainly guided by the existing research on the number of participants in qualitative studies and need for an ample number to cater for loss to follow up and sufficient numbers needed for grounded theory development (Guest and Bunce, 2006). A sample of 121 catered for attrition and loss to follow up. Furthermore, variation amongst the three sites meant each hospital had to have sufficient numbers for treatment pathways to be generated. The study followed up a total of 57 participants at 6-9 months. 22 of them had a repeated measurement at 12 months post-surgery. This ensured validation and member checking on some of the information they had provided at 6 months, and a fair comparison of what changes if any in their narrative of return to normal life. Multiple narratives were advantageous over one-off narratives that are ill placed to fully document experiences and offer succinct comparison over time. Data collection for phase two was conducted between February 2014 and December 2014. The entire data collection exercise was conducted over a 17 month period from May 2013 to December 2014.

3.5 Methods of Data Collection

The study used qualitative methods of data collection namely narratives and in-depth interviews. Interviews were held in Kiswahili or native language for the women and English or and the study tools were thus translated in the two languages. Specific data collection methods are discussed in detail below. Quantitative data were obtained concerning the demographic characteristics of participants.

3.5.1 Narratives

Narratives are a way of carrying out qualitative research by analysing stories or experience. ‘Narratives can be both a method and a phenomenon of study’ (Creswell, 2006). As a method, narrative begins with experiences as expressed in told stories of individuals (Creswell, 2006) and are an ‘interpretive approach that seeks to enter the social world of those who are being researched in order to gain understanding of their world’. The method is an extensive form of in-depth interviewing with emphasis on the individuals life story, or an event in the individuals life.

Narrative method was used with patients with obstetric fistula using a narrative guide to establish their experiences with the illness (Bernard, 2005). Particularly, the narrative guide for phase 1 focused on the participants’ health seeking patterns in the quest for healing and how they coped with the illness. Appendix 3 is a copy of the narrative guide used during phase 1 and the demographic profile sheet. The narrative guide for follow up in phase 2 focused on reintegration of fistula patients. Appendix 4 shows the narrative guide that was used in the follow up phase of the study. Narratives were tape recorded and note taking was done to guard against technological failure. Recorded interviews were translated from Kiswahili to English and transcribed. Data collected was used to establish treatment pathways participants followed during fistula illness.

3.5. 2 In-depth Interviews

In-depth interviews are a ‘one-to-one method of data collection that involves an interviewer and an interviewee discussing specific topics in depth’ (Hennink et al., 2011). The method is used to gain in-depth information about a person’s experience, feelings and perspectives on a topic. It is especially useful in studying sensitive topics.

Three groups were recruited for in-depth interviews namely family members, community members and healthcare providers. Selected family members, either a spouse a parent or / sibling to the participant was identified by the participant then, upon consent, interviewed during community follow up phase of the study. Questions covering topics such as coping strategies, health seeking behaviour patterns of patients, the role of family in influencing patients’ choice of therapy and support towards their reintegration were posed. Recorded interviews were translated to English and transcribed. The in-depth interview guide used to interview family members is presented in Appendix 5.

In-depth interviews were held with health care providers as key informants with the aim of mapping the health system response to women suffering from obstetric fistula. Key informants included nurses and nurse midwives, social workers, counsellors and community health workers. An in-depth interview schedule was used. The focus of the interviews was to establish the support accorded to fistula survivors upon first contact with the formal health care system. This yielded qualitative data concerning the formal health care system response to obstetric fistula survivors. An in-depth interview guide used to interview health care providers is presented in Appendix 6.

3.6 Data analysis

Data obtained included participant contact information; audio tapes; transcripts; GPS points for home location. The researcher then checked quality of tapes and transcripts before importing into NVIVO project. The tapes were translated and transcribed by one

research assistant for consistency. For interviews conducted in the interviewers' native language, they were translated and transcribed by the same interviewer in English. Data from both narratives with women with fistula and key informants was triangulated during analysis, and the results section present views from both fistula patients and their family members.

The researcher imported word documents into NVIVO 10 computer software used to manage qualitative data. The information containing participant background characteristics and contact information were managed using MS Excel for quantitative data. All research materials were kept in files in a locked shelf and were only accessed by the research team. Although procedurally, the information would have been availed to members of ethics committee and sponsors upon request in writing, no such request was made during the study. Confidentiality of participants' data and anonymity was maintained by the documents and materials being stored under a unique identifying code by the researcher. The list of identifying code was kept separate from the rest of research materials. All files were consistently named using the unique identifying code for easy retrieval.

Grounded theory techniques

Open coding was conducted for the first 6 narratives and researcher identified as many themes as they emerged relevant to the study and defined them in properties. Using line by line and in-vivo coding gave a sense of what the participants were saying in relation to the themes and meta-themes. It helped focus on the participants emphasis and emerged the initial 16 themes and 67 sub-themes. The subthemes were retained as categories that further describe the overarching theme and capture variations among participants and sites. Incident coding for the next thirty narratives with the 16 codes in mind produced 18 focused themes. Focused coding for the rest of transcripts analysed, the most frequently occurring themes were sought out and their properties fully defined. In NVIVO 10 project,

the use of functions such as coding queries and reports helped visualise the emergent themes and relationships between different themes. For instance, cluster analysis showed content appearing coded close to each other. These emergent themes are presented in the results section in the next chapter.

Data saturation and theoretical saturation are key concepts in grounded theory methodology that should be made explicit by the researcher. Guest et al. (2006) define data saturation as ‘the point in data collection and analysis when new information produces little or no change to the codebook’. On the other hand theoretical saturation is assumed ‘once all the main variations of the phenomenon had been identified and incorporated into the emerging theory’ (Guest et al., 2006). While data saturation may be obtained with a few interviews, theoretical saturation may require more interviews until the description of the category is exhausted. For instance, Wilson et al., (2002) used 66 interviews for developing a grounded theory on HIV/ AIDS reconciling incompatibilities theory. Guest et al. (2006) suggest that for meta themes, saturation occurs earlier in the process than if fine grained themes are sought. However, the optimal context supporting these meta themes may emerge later. The authors argue that 6-12 interviews are not enough in a heterogeneous group, when data is of poor quality, if the domain of inquiry is diffuse or vague or if an objective is to assess variation between distinct groups (or correlation among variables). One can use 12 interviews if the aim is to understand common perceptions and experiences among homogeneous groups but not to explore variation.

In this study, data saturation was reached at the 18th narrative for health seeking behaviour themes. However, about 26 narratives developed the first VVF centre’s treatment pathways in keeping with theoretical saturation. To confirm theoretical saturation, an additional 9 interviews did not further alter the treatment choices nor introduce new pathways.

In this study, since the three recruitment centres were located in different geographical locations in Kenya, it was imperative that each VVF centre's pathway be examined before a composite pathway is developed. A composite pathway had to demonstrate theoretical saturation, with all the possible variations of health seeking behaviour pathways of obstetric fistula patients being incorporated.

The homogeneity of fistula patients lies in their having developed the illness at childbirth. However, the sample was considered heterogeneous basing on, first, the varied individual background characteristics of age, level of education and geographical location. In addition, the narratives were highly unstructured and exploratory, necessitating an 'open-minded' approach to saturation since new themes emerged as late as at the 18th narrative. The third basis was the realisation that establishing the correct cultural belief/ agreement about broad domains such as health seeking behaviour and treatment pathways, or what entails reintegration of fistula patients would be better achieved by sampling quotas of not less than 30 at each site. Deliberate search for extreme variations of each concept in the theory was undertaken in observing the general rules of theoretical saturation.

3.7 Data Quality Assurance

There are several principles of data quality assurance and management in qualitative research (Reynolds et al., 2011). I ensured quality assurance in the entire process of conducting grounded theory techniques, as well as in the final outcome of the research. In summary, the activities that ensured salient process included the researcher bearing the greatest responsibility of decisions made in the research process; adhering to all ethical measures required for human research; and the systematic approach to the techniques of grounded theory research.

The researcher and research assistants kept a field diary to document happenings and write reflective notes that would inform final analysis, as well as help the reader understand how decisions were reached and interpretations were made. Debriefing meeting and conversations intended at keeping the quality of information obtained from research participants were held regularly in the study team. The quality of the research was ensured in its output from triangulation of data sources from participants, family, community, key informant. Peer review of findings in PhD seminars also contributed to validate the research.

3.8 Training research assistants

Research assistants with a background in anthropology and sociology were trained on the objectives of the study, the study methodology and research ethics. During data collection, the research assistants helped in conducting narrative interviews and transcribing some of the tapes conducted in their native language. One research assistant was dedicated to transcribing data throughout the research. One research assistant, a public health graduate student helped code part of the project in NVIVO.

3.9 Ethical considerations

Ethical approval from the Kenyatta National Hospital /University of Nairobi Ethics Research Committee (ERC) was obtained for the study on 4th April 2013 under ERC project number P618/11/2012. An application for the annual renewal of the approval was granted in February 2014 for the study to proceed to conclusion.

Informed consent was sought, where a consent explanation form was used to explain the research and the participant's role should they participate in the study. Later, participants verbally assented to and signed an informed consent form prior to all interviews and group discussions. The right of study participants to withdraw at any point in time was

communicated to them and strictly observed. Anonymity of study participants has been maintained throughout all stages of the study by use of code numbers. During community follow up visits, the researcher ensured we disguised such visits, not revealing information to community members without the express consent of participants. In cases where community members were interviewed, the participant gave express permission to do so and participated in identifying who would be most suitable to be interviewed. In cases where the spouse was interviewed, we ensured that there was no spill over of information obtained from the participant to her spouse so as not to cause unnecessary marital strife.

Ethical challenge of evoking emotional distress when survivors recount their experiences was once encountered. This challenge was dealt with by linking her with a professional counsellor resident in the hospital to help them. Furthermore, patients in the community found to be in need of medical attention were offered relevant information and referred to a local fistula repair centre. Thus the researcher worked closely with the health facilities and NGOS in each region to refer women who were identified to be in need of medical and psychological assistance. Research assistants were trained on research ethics prior to commencement of the study and those who joined. The ethical clearances to the research and consent documents are presented in Appendix 9.

RESULTS

The results section of this thesis is divided into three chapters, given the rich qualitative data that was obtained. This approach has enabled the data to be sufficiently interrogated under each study objective and provide room for ample illustrations without making the chapter bulky. Chapter four examines the objective of establishing how fistula patients live with and cope with fistula illness. Chapter five presents results focussing on the health seeking behaviour and reintegration patterns of fistula patients. Chapter six presents results focusing on the reintegration of fistula patients. For easy readability thus, the results section has been divided into three chapters.

CHAPTER 4: LIVING WITH FISTULA AND COPING STRATEGIES

In this chapter I argue that the onset of fistula illness presents a crisis to the woman, who from a previous normal life and pregnancy is plunged into living with a shaming and distressing illness. They cope with illness by concealment using self-isolation and strict hygiene, but often, the symptoms are revealing and the women have no control as to who is privy to their illness. In addition to this individual coping mechanism, the presence of social support from the spouse, natal family and community help women cope with fistula illness.

The first part describes the characteristics of participants whose composite treatment pathway is presented in this chapter. In keeping with the basic tenets of grounded theory methodology, the participants' characteristics are analysed together with the and alongside the qualitative data. Although inferential statistics would be useful, in this case they are not performed. Constant comparative coding is instead used to, for instance compare the narratives of younger women to those of older women; those with children to those who have no surviving child. The remaining sections particularly focus on the onset of illness,

cause of obstetric fistula illness, how participants recognised its symptoms and how they responded to these symptoms in terms of health behaviour and seeking treatment. The chapter also triangulates data sources from in-depth interview by their family members. Participants' names and contacts were obtained in phase 1 for purposes of follow up. However, throughout the thesis, a unique identifying code number replace the participants' names to protect their identity. The county name is provided instead of village name because such disclosure could inadvertently reveal the identity of participants in case she is the only one with illness in that village, even without her name. In instances where a participant mentions a name in a direct quote used to illustrate a point, the names have been replaced with four asterisks as ****.

4.1 Characteristics of Participants

Phase 1 recruited a total of 121 participants. All study participants had received free corrective surgery for obstetric fistula. However, they had diverse background characteristics namely age, geographical location and level of education. Partly, this sample size was in keeping with deviant case analysis that is a requirement of grounded theory analysis and in the heterogeneous nature of fistula patients.

Most women at the time of study were young with a mean age of 33.2 years (median 31, mode 28). A wide age range, from adolescents aged 17 years to postmenopausal women of 62 years is represented in this sample. Most women had developed obstetric fistula at a young age with mean age at which obstetric fistula occurred being 23.2 years (median 22, mode 18). Appendix 1 presents the profile of participants by background characteristics.

The study participants came from 30 counties in Kenya at the time of hospital site recruitment. The geographical distribution was partly affected by one surgical camp that mainly drew participants from the same county, compared to the other two study sites

whose participants are widely distributed over several counties. Though most women hailed from the rural areas, a few resided in the urban areas.

Notably 12.6% of participants had no formal education, 7.6% had lower primary education (P1-4). A majority (47.1%) had attained upper primary school (P5-8) as the highest level of formal education. Only 27.7% of participants had obtained secondary school education. A paltry 5% of participants had attained college education signifying a low level of education among women suffering from fistula. Women with college education lived with the illness for a shorter period except two who spent 3 and 8 years respectively. This disparity is unexpected given the level of education and expected better agency at seeking treatment associated with higher level of education, and points to the difficulty with which women of varied levels of education have little access to qualified fistula surgeons. Moreover, occurrence of fistula illness amongst women with a college education deviates from the typical 'poor illiterate women and girls' mostly reported in fistula research. The socioeconomic status of the women was not evaluated even though all had received free corrective surgery.

Regarding the number of children alive, 35 women had no surviving child representing 29.7% of all participants. Further 22% (n=26) women had only 1 surviving child, and 16.1% (n=19) had two children. Only 32.2% of participants had more than three children. In a country where the average fertility rate is 4 children per woman, it seems many were well at the start of their reproductive career when fistula occurred. This is more so revealed in the participants concerns about regaining their fertility after fistula surgery, as presented in chapter five.

Women had lived with fistula illness for a period ranging from less than a year to decades before the first corrective surgery. Section 4.3 describes the period of living with fistula in detail. They also had previous surgeries to the current one and had paid multiple visits to

different hospitals while seeking treatment. The total number of hospital visits prior to the current VVF surgery ranged from three women who were experiencing the first visit to one who had surgery on the tenth visit, with an average of 4.15 hospital visits per woman.

Regarding the number of times women had undergone fistula surgery, 66.7% of participants had their first reparative surgery at phase 1 of the study. However, about a third of the participants (33.3%) had undergone a previous corrective surgery for fistula illness. A few women however reported an extremely big number of previous corrective surgeries. For instance, while 15 participants (12.8%) were having a second surgery, 4 (3.4%) had their 5th surgery and a further 2 participants (1.7%) having a sixth surgery. The lifetime total number of obstetric fistula corrective surgeries ranged from one to six. From this finding, about a third of women were undergoing further surgery following previous unsuccessful surgery. The reported high number of surgeries, indicate the complex nature of fistula surgery and likelihood of need for multiple surgeries to correct the anomaly. In a previous era of few qualified fistula surgeons, this finding could also point to some surgeries being attempted with insufficient skill for fistula repair.

4.2 Crisis, Concealment and Disclosure at Onset of Fistula Illness

The onset of fistula illness begins with the index delivery and events surrounding it provide a contextual understanding of how fistula occurs and the crisis presented by the onset of fistula illness. Examining the context surrounding the index delivery is therefore necessary to insight on how obstetric fistula illness occurs and the subsequent conditions of responding to the illness. Here, the distress that ensues upon realisation of the most recognisable symptom to the participant is tied with feelings of shame and concealment, and ultimate disclosure or self-disclosure to family and the beginning of seeking treatment. It is at this crisis that women begin to strive to correct the abnormality and regain

normalcy. It also marks the beginning of an unpleasant experience of living with fistula, an illness that often assumes a chronic nature.

4.2.1 Index Labour and childbirth

By definition, obstetric fistula is caused by prolonged obstructed labour and childbirth. Thus, as pre-requisite, women were asked to narrate their labour and childbirth experience around the period when fistula illness occurred, the index delivery. Four salient issues present in the women's accounts of their antecedent labour and childbirth experiences.

First, women had extended periods of labour pains at home. Secondly, they were assisted during labour by an unskilled birth attendant identified as a family member, friend, neighbour or traditional birth attendant or a combination of these individuals. They would either deliver the baby under this unskilled help or eventually arrive at the formal healthcare service delivery point. Third issue that arises is that of referral during obstructed labour to a facility that could be able to conduct assisted vaginal delivery or caesarean section. It thus starts off many women narratives having delivered in hospital though the previous two salient issues are key contributors to the outcome of both fistula illness in the mother and at times death of the neonate.

The fourth overarching issue here is that although most of the women describe a hospital as the ultimate birthing place (n=84), they had poor birth outcomes like stillbirth and formation of vaginal fistula. For instance, concerning the place where the woman delivered the baby prior to developing fistula illness, 77.3% of women reported to have delivered in hospital, and 19.3% delivered at home. 3.4 % delivered at the home of or with assistance of a Traditional Birth Attendant (TBA). But closer scrutiny reveals that for the 84 women who delivered in hospital, the mean estimated time spent in labour before reaching hospital was 34.6 hours, (median 17.5: mode 48) ranging from 1 hour to 168 hours. There is a lot

more time spent outside hospital and skilled delivery care by women who develop obstetric fistula.

In this study, 35 women had no surviving child from the antecedent labour, resulting in a stillbirth. There is a tale of agony, having lost both the baby and developed vaginal fistula illness at the same time. For instance, a participant described her birthing account as is typical of fistula patients in this study. She had prolonged labour at home, was assisted to deliver a stillbirth through caesarean section and developed VVF in addition to nerve injury that made her hospitalised for four months. At 24 years of age, without a child and separated from her husband she narrated:

It started when I was pregnant, then it reached time to give birth but I delayed in the house a lot for almost four days. Then I was taken to hospital, I went to Nyamira hospital and I was operated on. After the operation, the baby died. I then stayed in the hospital for four months as they continued treating me. It reached a point where the wound that was stitched opened. I continued with treatment until I was well. After treatment when they removed the catheter, I found the water [urine] coming out and it was a lot. I then asked the doctor “how will I go home with the water flowing?” He told me that “If you continue taking a lot of water, the wound will heal.” I continued drinking water and noticed it was reducing; it was coming a lot but it started coming slowly. (006_3, 24 years, No children, Nyamira)

A typical quote that illustrates the point of home delivery is that of a 32 year old woman with secondary education who got VVF on her second delivery:

I delivered when I was at the house in my home [...] There were midwives [TBA] and just other women. You know when women at home hear that a certain girl is giving birth they all bring their eyes. Everyone tries [...] it now became difficult and so the women had to pull the baby. (006_2, 32 years, 5 children, Machakos)

Moreover, the complexity of traditional birth attendance, referrals, lack of money and time spent in transit between referral points culminate in development of fistula, as this participant's quote demonstrates:

I told that midwife [TBA] to tell my husband that I have been defeated and he should take me to Mumias Mission Hospital. My husband saw the money for the mission hospital was a lot it would be better if he took me to Butere. Now when we went up to Butere there was no doctor who could operate on me. They put me in an ambulance and took me to Kakamega. When I arrived at Kakamega General I found an Indian doctor who examined me and took me to the theatre. (028_1, 28 years, 2 children, Kakamega)

Typically, the woman, once in hospital, is assisted to deliver through assisted vaginal delivery or caesarean section. The baby would be resuscitated or a stillbirth, demonstrating that often, the events around formation of obstetric fistula not only harms the mother, but also the baby. Some participants when asked what they thought had caused the fistula at the time of its occurrence, linked it to the caesarean section operation or other assisted delivery procedures they underwent. Though this reasoning is 'unscientific' in their world, from an emic perspective is what represents assumed cause of their illness. What the participants are not aware of in this instance is the idea that a prolonged period of labour pains could have caused the fistula, even before caesarean section. A quote that best illustrates this point is from a woman who had her baby resuscitated:

They took him and said, 'it is not even crying', they held the baby by the legs, put him upside down, and patted it and the baby still did not cry so they went. And because I had been in so much pain, I found myself sleepy and so I slept totally. After almost forty five minutes, that's when I saw the Sister come to me. I had felt them put the baby by my side. You know when you are even asleep you can feel them placing the baby by your side. They patted me and said, 'there is your baby'. Looking at it, I found out that the head was so elongated. (005_2, 36 years, 2 children, Kiambu)

In these three atypical cases presented, the participants had a surviving child or got children after development of VVF. Some women however are not as lucky to have a surviving child and have to deal with this loss, often permeating their reintegration narratives.

4.2.2 Symptoms and their Recognition

Onset of symptoms of fistula illness sets off a crisis to the women. Often, it is a time when they notice a deviation from normal bowel control and either reach out to family and healthcare providers or conceal what they perceive as shaming. In reaching out, there is chance for proper diagnosis and vital linkages to care for the women who develop obstetric fistula. The healing and regaining normalcy process starts at this point of crisis and lasts up to when the previous normal state as before illness is obtained. Thus, the women start

moving along a continuum of healing and exhibit health seeking behaviour that they reckon will regain normalcy.

Some women may mistakenly think that urine incontinence is a normal occurrence after childbirth and naively wait for the symptoms to remit and illness to heal on its own. In such cases, a healthcare provider informs the woman of her illness. A typical quote that illustrates this point is derived from a participant who at 25 years when the fistula occurred, did not know what it was until three years later when she was screened and was informed by the doctor the nature of her illness and how it is treated. This participant waited for over three years for a return to normalcy which wasn't to be realised.

I did not have an idea of seeking medical attention or care. I thought it would stop. I thought may be the muscles had become weak after the cleaning. I thought it would just stop. [...] He checked me and told me that I had fistula. At the time I did not even know what fistula was. So I asked him what it was. He told me that fistula is the condition in which the urine was leaking. He told me that he would refer me to the place where I could get assistance and I will be able to get the necessary assistance. (001_2, 31 years, No children, Nairobi)

However, in many women's cases, though they recognised the symptoms of incontinence whilst still in hospital, diagnosis, proper information on the nature of illness and referral to treatment was delayed. This missed opportunity contributes to the length of time lived with illness hence the chronicity of fistula illness. Missed opportunity in diagnosis also reduces chances of prompt treatment and better surgery success rates for the women. For instance participant 007_01, a 38 year old woman from Busia did not know the name of the illness she had, even as she left a district hospital where she had undergone caesarean section surgery. At the second facility, the nature of the illness was not made clear to her, until she went to the third hospital in Maseno. It took her two years and four hospital visits to know exactly what she was ailing from and get her first corrective surgery. Ideally, the naivety of women regarding their condition should have been remedied by the health care system,

which unfortunately did not. Here, questions arise as to the ability of healthcare providers to properly diagnose women with fistula and refer appropriately.

The gap in diagnosis and information at the first point of contact with the formal health care system often leaves the woman not knowing what condition they have and if it may be remedied. It may contribute to long times spent with illness as shown by the treatment pathways of fistula patients in this study. This contributes further to the emotional turmoil of the women regarding their condition.

Symptom recognition starts the period when a woman seeks for remedy, assisted by or accompanied by their kin. To women with vaginal fistula, the symptoms are not only distressing to them but to the family and friends they confide in. The recognition of fistula symptoms is often devastating to the family members as well. The distress caused by realisation of fistula illness was described by a participant's grandfather who captures the surprising and shocking nature of fistula illness and the patient suffering. Although he ultimately expressed hope now that their granddaughter was 'healed', there was a tone of dissatisfaction regarding the 6 months she lived with fistula, when in his words, 'they were going to hospital but they were not able [to treat her].' He explained:

After she had delivered she contracted the illness. Dirt was just coming out. She used to stay here, a lot. I was even shocked and then we were surprised how she would get treated. Will we find doctors who can treat this illness? Then we suddenly heard the radio announcing about their illness [...] that there were doctors who were coming from Nairobi. (KII 001-3, Grandfather, Kisii)

At the start, hygiene issues present challenges to women's normal social interaction. Gradually, it implodes into questions as to whether the woman will reproduce again, and has impact on her marital life, relationships and gender role and economic activities. She then experiences the full range of moral properties of suffering and living with fistula, concepts that are presented later in this chapter. The interplay between disclosure and concealment, however, offers succinct ideas into what this crisis presents to women. On

the one hand, it is a shaming illness and should be concealed, but on the other hand, it is hard to conceal and the illness 'self discloses' to those who are intimate to the woman. Here, the tension between controlling disclosure and getting help present dilemmas to the woman.

4.2.3 Disclosing illness versus concealment

Often, since the women themselves do not understand this illness, it is difficult for them to disclose. Women often avoided disclosing illness until it was inevitable. At times spouses and relatives observed the symptoms on their own and initiated conversation around the illness. This reluctance, coupled with expressions of fear and shock highlight the difficulty women who suffer from obstetric fistula illness have to transcend to talk about their condition and get support from those close to them.

Besides, it is an illness concerning the functions of bowels and introduces hygiene issues which attract embarrassment. For instance, a participant who concealed her condition explains how she isolated herself from social interactions like visiting other people's homes to avoid embarrassment. With college education and one surviving child, she was able to obtain surgery within less than a year after four hospital visits. Though the first surgery had regained her urinary continence, she still had faecal incontinence. She explains how avoidance and strict hygiene helped her conceal the fistula illness:

I did not tell anyone about the problem. It was only me who knew that I had a problem. When the pad got soaked I would just rush home and change it. The only problem was that I could not visit other people's houses. You see when you visit other people they may start wondering about you. And you know when the urine exceeds it will start leaking and I did not want to get embarrassed in other people's homes. (022_1, 24 years, 1 child, Kakamega)

Disclosure by the woman about her illness to her husband not only present embarrassment but possible rejection that would come with this disclosure. The participant below narrated

a conversation she had with her husband that changed his attitude towards her, eventually ending up in separation and abandonment.

I was the one who did wrong and told my husband [about my illness]. He asked me 'how are you staying?' I told him 'now what will I do?' He now asked me 'the faeces come out from this other side?' I told him 'eehh [yes]'. Then I started seeing somebody changing. He wrinkled his face! He doesn't want to look at me. Now after 3 months he even started refusing to give me help. He relocated with his clothes and went away. I couldn't explain to anybody else because I wasn't thinking that this problem could not be treated. That is a shameful thing. Because you will tell another person they go saying you see this one she relieves on herself the faeces, this one you even can't stay with her. That is people start fleeing away from you. (018-2, 27 years, 2 children, Kiambu)

Due to the nature of recruiting process, we were not able to interview men who had separated from their wives due to fistula illness. However, the men who remained married to the woman after she develops fistula offered opportunity to highlight what this illness means to them. Granted, fistula illness poses hygiene and psychological aspects to men whose wives develop obstetric fistula.

Participants with RVF found it easier to conceal the illness symptoms, being biologically easier to regulate and time passing of stool than that of urine. Some women with RVF did not disclose the illness to kin and friends and some even managed to hide it from their husband. However, the un-concealable nature of urine incontinence made it harder and necessitated disclosure on the patient. For some women, their kin and close friends 'saw for themselves' the incontinence and discussed with the patient or doctor. It was not in their control to regulate who knew about the illness and who did not. In this sense, the lives of RVF patients were less disrupted than those of VVF. Indeed, this existing difference impacted on their social interactions differently as demonstrated in the later sections of this thesis. Concealment was more common amongst women in the urban set up as practically the social setting is more business-like in the urban areas, unlike in rural area that is more closely knit and people more inquisitive of others' lives.

Often, the doctor or another healthcare provider has to disclose the illness to family, acting as a 'bridge' to the patient and her social support network. This offers the healthcare

provider an opportunity to give accurate information about vaginal fistula and its causes and management to the family.

The tension between disclosure and concealment determines who a woman shares her problems with, the accompanying reactions and any help or linkages to fistula care. It is therefore an important crisis point in the women's illness and health behaviour trajectory, an opportunity for intervention by friends, family or healthcare providers.

4.2.4 Health system response to fistula illness

Prompt and correct diagnosis is the first step in formal healthcare treatment pathways that are most useful to participants and most desirable response to their disclosure of illness. In the event that proper diagnosis is made, the woman has to be linked to a hospital that does conduct reparative fistula surgery, with facility and skill to do so. Lastly, the surgery cost should be affordable for the woman. These three health system issues interwove in participants narratives and seemed to add to the complexity of health behaviour. However, participants' fear of surgery, previous experiences and other individual factors determined the timing and place they sought help from.

For instance, participants though properly diagnosed and referred, did not promptly look for treatment. This is demonstrated in a case where healthcare providers diagnosed a woman with VVF that she had from her first delivery during the birth of her second baby, and offered her surgical treatment. She did not however have the money and together with her husband decided to go back when they got money.

I gave birth in January 2003. I was taken to another hospital in our area called Tigoni. So when I was taken there I gave birth well and had no problem at all. The female doctor who helped me deliver told me, 'woman, do you know that you have a problem?' [...] They said that the anal tract has been joined with the birth canal and even when the baby has come out, it has come out with faecal matter, and I mean dirt. They told me that when my husband comes I tell him so that they can take me to the theatre. When my husband was told that and because he had no money and paying the bill so that we come from the hospital was problem, he told me that when we get money, I would come for treatment then. I was not treated at

that time and so I went back home with the problem and it has been like that till now. (005_2, 36 years, 2 children, Kiambu)

Lack of money for operation costs is not the only barrier to women accessing treatment. The lack of proper linkages with vital health facilities that have surgical skill to treat VVF was a common thread in participants' narratives. For instance, this participant conceived, laboured and delivered twice in a health facility who properly diagnosed her illness. However she lost contact with the healthcare provider who was her link to treatment thereby lost opportunity for earlier treatment. She explained:

In 2006 the time I went to deliver I went to the hospital. After delivering the doctor who was in that hospital told me hey you have got a child but the thing that I should insist on, you go look for the place you can be done correction. Your passage for delivering was torn a lot. These two doctors came and told me. [Baby] Number 4 I was told by a different doctor. I have a problem I look for somewhere go for repair. And when I was coming to deliver the other one in 2009 I found another nurse she told me that thing. She told me '****', it is required when you get well there is another program which comes of fistula. If you can be available I can book for you space. You can go be repaired'. So the time I delivered we moved out from there we lost touch with that doctor. (006_2, 32 years, 5 children, Machakos)

From the participant's narrative, lack of contact with and linkage to care was her greatest problem. To overcome such challenges of contacts and linkages, Gynocare fistula centre used phone calls to contact patients and link them to care. Their regional representatives too used phone calls to coordinate movement and care of their participants, making it easier for estranged or immigrated patients to still access care. Information and communication technology like radio advertisements and phone calls have assisted health workers to link women living with fistula repair camps and centre in Kenya. This development in patient care may be used to conduct follow up during the postoperative period and could play a role in their reintegration as demonstrated by the Gynocare centre.

The greatest impediment to women obtaining timely treatment was the missed opportunity for proper diagnosis, information concerning the type of illness and referral to where such illness would be treated. A participants spouse explained:

When she was still in hospital, she had the symptoms of this illness. When she asked the doctors there they said ‘it will be like that for just a few days but you will be well’. All the rest were healed but in that hospital, my wife became if its stool, it’s coming out. It has no brakes. If it is urine, it is just coming out, when we ask the doctors from Russia [general hospital]. They say, ‘aah, she will be well’. Because the way she has been stitched, and the stitches are not yet set. She will just be good. After staying, we saw that she did not change. On returning her there, whatever we got was different. They said if she wanted to be taken back to [theatre]... five thousand [shillings]. (KII 006-1, Husband)

This quote from a participant’s husband best expresses the frustration he faced whilst assisting his wife to get treatment for fistula illness. At the start he was not fully disclosed to the nature of the VVF illness. Instead he was misinformed that ‘once the stitches settle, she would be continent of urine’ and discharged. Here, an opportunity for early diagnosis was missed. Later, the other obstacle that arose when he took her back to hospital was monetary in terms of the fees required to be paid before his wife could be treated. Faced with these challenges, he decided to stay home with her. She, on the other hand described her response to the fistula illness thereafter as a situation of living with fistula illness, saying ‘I stayed with my illness’.

4.3 Living with fistula

Living with fistula is a stressor in the women’s lives given the emotional, physical, social and economic consequences of the illness. Women also take a long time living with an illness that is curable and should ideally be treated promptly. The moral properties of living with fistula entail suffering, shame, stigma and isolation

Time lived with illness

Inadvertently, fistula becomes a chronic illness that the woman has to manage. For some women, the time within which they had to experience these stressors was limited, obtaining surgery in the immediate period. However, a lot more women lived with fistula illness for years experiencing greater stress. In summary, women lived with fistula illness before this surgery for time ranging from less than 1 year to 39 years (mean 8.9, Median 6,

mode 7). Similarly, time women spent before a corrective surgery ranged between the immediate period (n=4), less than one year (n=26 women), 1 to 5 years (n=37) and 6-43 years (51). Many women had lived with the illness for longer than 5 years depicting obstetric fistula as a chronic illness. Figure 4.2 below demonstrates participants time lived with obstetric fistula illness:

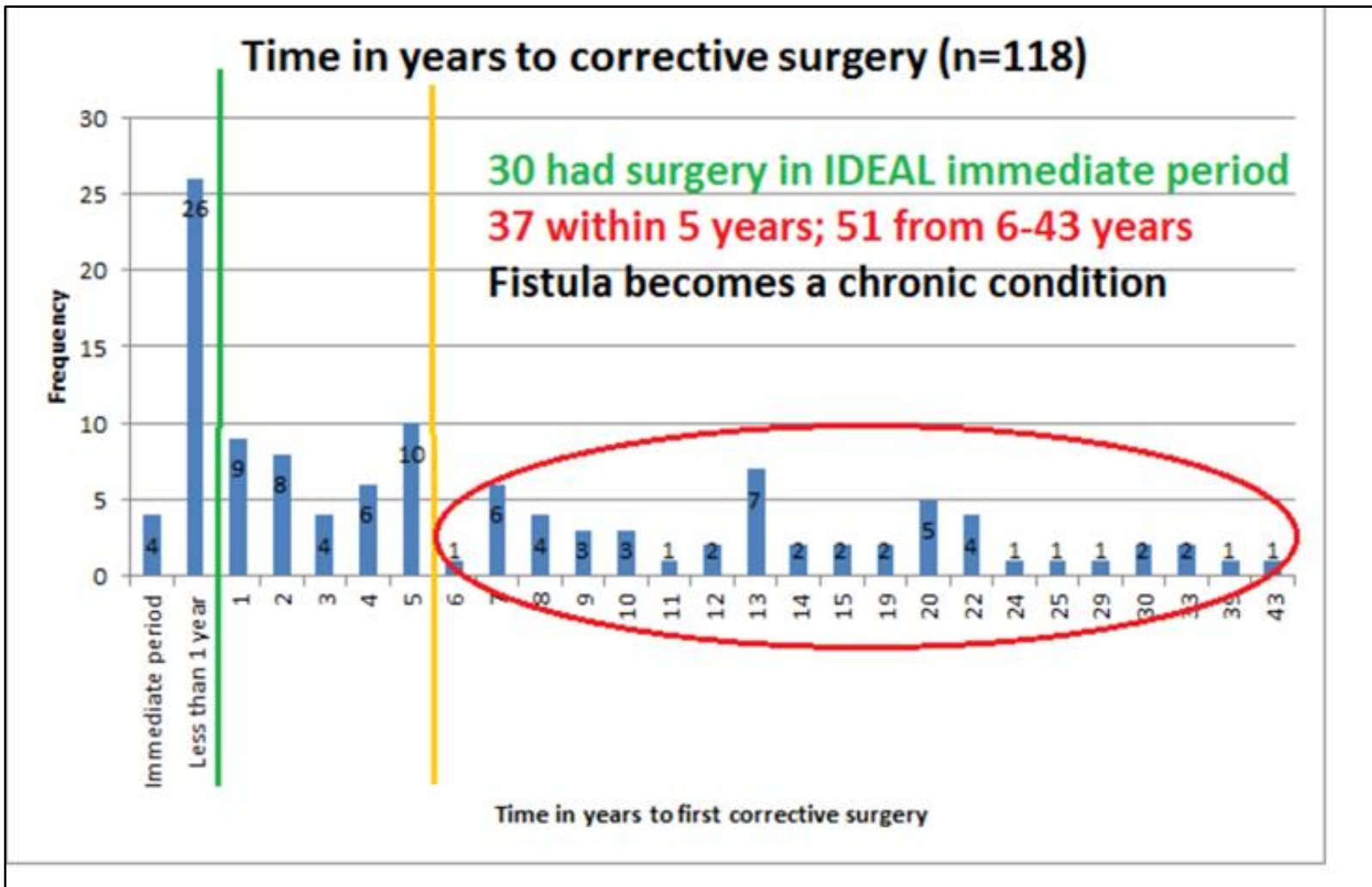


Figure 4.1: Time lived with obstetric fistula illness

Moral properties of living with fistula

Themes of having negative psychological thoughts, social isolation and suffering overlap in the women's narratives and allude to the moral properties of living with fistula. Although the women rarely refer to suffering directly, their narratives depicted feelings of helplessness, sadness, emotional pain and shame. Occasionally, suicidal thoughts and feelings of (perceived) imminent danger of death from the illness permeate women's narratives of their lives with obstetric fistula. These are properties that define their experience of suffering. At times, they refer to their illness as a 'problem' *shida* (a term which in Kiswahili that refers to a situation in one's life that needs *msaada*' help. Content describing women's suffering closely follows or links with their isolated lives and the mental anguish they experienced whilst living with fistula.

One significant finding in this study is the time women spent with the illness without being treated. In their own words, they said '*I stayed with my illness*'. I sought to fully describe what this in-vivo phrasing meant. First, this alluded to the long time when some participants thought it was the way of life that came with begetting a child whilst others it was just that they did not know its treatment existed, as narrated by 005-2 in the following excerpt.

I thought that because it was the first child, I thought that everyone is like that and so I was quiet about it. When I went somewhere, or want to go somewhere, am afraid that when I eat something, food, I would have a problem of faeces. And so I was forced to take two clothes with me everywhere I went because I would find that I had soiled the dress that I had and would look for water so that I can wash it. (005_2, 36 years, 2 children, Kiambu)

Staying with obstetric fistula illness meant suffering, flawed hygiene, social isolation, and sexual and marital challenges, at times leading to divorce and separation.

Suffering

Feeling helpless, sad, shameful, lacking peace of mind and being in a state of general problems are the hallmark of women's tales of living with fistula. The complex hygiene

and social challenges posed by fistula illness culminate in a moral state of suffering. For instance, this woman had fistula at the age of 16 years and lived 13 years with the illness having had two corrective surgeries. She felt unable to enjoy life as she explained:

I had a lot of problems; I could not do anything for myself, I just stayed at home with problems. At home we are not well off so I went to stay with my sister at least to get food, to bath and just stay. I never had peace even and could not stay with my friends. I never enjoyed life at all; I lived with problems. (031_3, 29 years, No children, Kericho)

Shame is a feeling women endure, and possibly affects the way they disclose illness and seek for treatment. The concept, though subtle, presented a lens with which to understand why a woman would want to not disclose her illness, why her care seeking trajectory was managed between few close family members or friends and the hospital. Shame explains why after surgery, women are still shy about other people being let in on their story and are reluctant for us to interview community members. Shame limits the people they disclose their illnesses to and makes it a personal problem, 'I stayed with my problem.' A classic example of women who felt shameful is presented:

I tried to hide because it is shameful. I did hide the problem for a while and didn't go to her [mother] place [...] I stayed at my place. I am not comfortable when at home. When you are with friends, at work, you are not comfortable because it is not a good thing. It is something to be ashamed of. (002_3, 40 years, 7 children, Nakuru)

The way women talked about their experiences is arguably the greatest pointer to what suffering they went through. A participant would pause between sentences, sometimes they would cry and other times they would not talk about the past. Perhaps, the pain and anguish of their life a few days prior to this surgery is yet an unexplored pain and the interview is offering an escape to this emotion. For instance, 059_2 first interview was discontinued because she broke down and cried. Having lost her husband who passed away two weeks before the rectovaginal fistula occurred, she got married to another man but was afraid to tell him about her condition, though she had pain during sexual intercourse she worried that he would ask her where she got that problem from. He often

got drunk and beat her up. At the time of interview, she had just given birth to another baby and was granted leave from her job where she worked as a security guard. Earlier, she had narrated the suffering and fear she had:

It has been a life of suffering. It makes me to think a lot to a point that I do not have peace of mind. I thought I would die, I don't know. (*Pause*) I do not have any one to help me. (059_2, 28 years, 2 children, Nairobi)

Often, they disclosed only to family and hid the illness from friends. Linked with other feelings of 'shame' 'shock' 'surprise' about the illness, suffering becomes a personal experience devoid of social support that would be offered to other patients with chronic illness like cancer that attract sympathy from friends. At the same instance, the concealment offered them the comfort of having to deal with stigma thus becoming a coping a strategy.

Stigma and isolation

Social stigma as experienced by the women is self-enacted or enacted by other people in her family and community. While the people surrounding her may avoid her due to practical issues such as a bad smell, at times they would discriminately not engage her in business or employment. At the family level, her illness would be a pivotal point which in-laws pitch against her for their brother or son to leave her. However, other times, the women isolated themselves, out of fear of being reprimanded, the embarrassment that incontinence brought to them and not knowing the nature of their illness. They did not have freedom. A quote that best illustrates the isolation occasioned by obstetric fistula illness is from a woman who had lived with the illness for 12 years:

I did not have freedom. I never had freedom at all. (*silence*) Because now you cannot sit with people, you cannot go to church, you cannot go to the market and do business, you cannot travel, you cannot be a visitor; it is like you are locked somewhere where you can't leave, you cannot turn, you cannot sleep, you are just standing. (*Silence*) that is how it was. (034_3, 26 years, No children, Trans-Nzioa)

But other times, in the market place, a woman who has obstetric fistula will not be able to sell her vegetables to customers who shun her, a form of enacted stigma. A participant explained how customers discriminated from buying her wares, questioned the hygiene of the products she sold, and falsified the manner in which she produced them to sound unclean:

Now these vegetables they would say ... they would ask [their children] where they had got the vegetables from, 'where did you buy it from? Did you buy from mama Chalo?' They say that I take the urine and plant the vegetables and also use it as the manure. 'I will not eat her food'. (010_3, 51 years, 1 child, Kisii)

Another participant presents the situation where enacted and self-enacted stigma interplay in the same persons situation. Other people had difficulty to come near her, and her feeling embarrassed to go near them ultimately led to her being isolated.

To tell the truth, I was really embarrassed. I was wet all the time that even when I go to church, I just sit behind. I could not sit where other people were because I thought I would smell in front of other people. Every now and then, urine would just flow. So when I sit somewhere, no one wanted to sit near me, most of the time I would just sit alone. Even when going to the market to buy things, I used to write a list of what I need [...] so I would be fast; I also had a motorcyclist ready who will take me back home. I never used to go any other place, even to see my mother. I only went to a funeral once and maybe to church but mostly I stayed at home. (12_3, 28 years, 4 children, Migori)

These three women capture between them a narrative of having to deal with limited or no social interactions as occasioned by fistula illness. Whether the isolation and stigma is self-enacted or enacted by others, her normal world is cut off. The hygiene issues that emanate from stool or urine incontinence are huge costs on time and money. Ultimately, the woman who suffers fistula is on her own and perhaps a close family member or husband with whom they have disclosed the nature of the illness.

Divorce and separation

Obstetric fistulae, presenting as urine incontinence or stool incontinence, cause marital strife to women. Of the 35 women without a surviving child, 20 were separated from their husband permanently or for a specified period of time. The remaining 15 were unmarried

by the time they developed fistula and were living with parents or grandparents. The illness presents women with challenges around three areas. First, hygiene issues made sharing a bed with the husband impractical. Secondly, women were not comfortable to have sexual intercourse as a result of the illness. Years of separation and estrangement meant the husband married another wife, or went back to his first wife in case the patient was the second. Third and final issue is that these challenges lead to separation and divorce and the abandoned woman is left to fend for herself, because he had nothing to come back to. With no living children, the husband almost always moved on, resulting in divorce and separation.

Discussions around difficult in sexual relations, separation and divorce were emotional, and often interspersed with awkward pauses and silence. For instance, we had a difficult conversation with a participant who had been separated from her husband during her illness. For this participant, silence, discomfort and tension surrounded the manner in which she spoke about her relationship with her husband. He had married a second wife after two years of living with fistula and not being intimate. It was an emotional subject for her.

No, I don't want. Now you smell of urine, how can you be intimate? [...] When he realized I had a problem. I refused to be intimate with him. I did not want. He married another wife. [...] We are in the same homestead. He sleeps in the other house. There is nothing to come for in my house. (012_1, 60 years, 5 children, Bungoma)

The point here is that whilst on superficially she is still 'married', a woman with fistula has been abandoned by her spouse who moves on to marry again. She often loses the support previously obtained towards living costs, though she is still housed in the same homestead. Other women however have to even forfeit the housing and go back to live with natal family or siblings. In the event that they had no such options, some women had to live

humiliated lives in their husbands' house sleeping on the floor on a sack as this participant explained:

He was so bored and started telling me that I should go back to my parents and that am not a person he can live with. My mother passed on this year [*sobbing*], so when he tells me to go home I could question myself where I was going. It is very painful. It was very bad to be told to go back at home and after mum's death my brothers did not want to see the sisters at home due to some rivalry, so I was wondering where to go. I just opt to go and rent a house and do a contract work in farms and I do not want to live with a man and just wait to get well. It is nice that the doctors have come but I want to get well and wait for the days that God has given me. It is painful... It is shaming and burning. The pain you go through is so bad [...] I was just persevering and staying with my husband because there was no place for me to go. (14_3, 30 years, No children, Kisii)

The woman has not only suffered the loss of her baby and developed obstetric fistula, but also has to face a new life devoid of marital support she previously enjoyed. Often, the natal family has to take care of women who were previously married. In the absence of this support, the woman has to fend for themselves but with the challenges of isolation and socioeconomic redundancy presented earlier.

Older women living with fistula with no surviving child and separated from the husband face a more daunting task than their younger counterparts. With time, their parents who were supporting them pass away and their siblings concentrate on their own family lives. This leaves them with little social support, in a world where they neither belong to the husbands' clan or their natal clan. The problem is best illustrated by an older participant:

My third operation was in Mumias. When I came from Mumias, my husband did not care about me, when he saw that I have gotten this problem, he saw that my life with him was over. [...] So I went through a lot of problems, a lot of problems and I was not staying at his homestead. [...] I was staying at home with my parents. (037_1, 50 years, No Children, Bungoma)

Although some women do get married and beget children after fistula illness, they were rare to come across. The dominant marriage outcome was that of divorce and separation as a result of fistula illness. Conducting deviant case analysis in grounded theory led to

examining how women coped with marriage, sexual relations and childbirth during fistula illness.

Marriage and childbirth during fistula illness

Marriage and even childbirth is possible during fistula illness. It is a positive note that women with fistula can continue their reproductive career amidst the challenges that living with fistula poses. The women manage their symptoms of the illness by concealment or masking of their condition from their spouses. However, other women's spouses knew of their condition but rarely understood the condition. A participant described her experience having sexual intercourse with her husband during fistula illness:

But when am with him [sexual intercourse] there are times when he slides and am in pain, so I tell him, just do like this or that or loosen a bit or something. He just knows that when we are together. (062_2, 31 years, 2 children, Kiambu)

Some women with the illness marry new partners and do have sexual intercourse with their spouses. With symptoms of urine or faecal incontinence, they manage these relations with support from spouses, observing strict hygiene, and at times, concealment from the spouse of the true nature of the illness.

The kind of spousal support enjoyed by women who remain married after fistula illness may not be available to their unmarried counterparts. Often, parents of unmarried adolescents are left with responsibility to seek for their treatment and sustain their living expenses. However, the fact that some women get married while suffering from fistula illness points to the empathetic role men may play in these women's lives; and the opportunity of involving men in supporting them.

4.4 Coping with illness

The deviation from normal bowel control, stable marriage and supportive social networks challenge the women to attempt to regain 'normalcy'. Women avoid social interactions,

observe strict hygiene and avoid eating food or drinking that would lessen output. The avoidance to take water was common among those with VVF.

I also stopped taking too much water. I would drink it sometimes and other times I didn't. When I drink water, the problem becomes worse but when I stopped, it was not that bad. Even when I sleep at night, I must put nylon paper. When I fall asleep, I would find lots of water on the bed. I kept on wondering what it was. I just continued praying hoping that God will help me. (035_3, 23 years, 2 children, Kisii)

Women resorted to employment that would not involve direct social interactions such selling firewood or picking tea. In instances that this is so in employment, they re-negotiated their working terms with the employer, especially in domestic workers. Non-disclosure was commonly applied by women who remained married or remarried.

Another coping strategy of women living with fistula is to avoid much public or social contact. Further, they concealed any symptom of incontinence by observing strict hygiene. Hygiene was a central part of women's coping with symptoms and in turn concealing the illness. It also restricted their scope of social interactions, depending on how well they could/ could not control their hygiene. Some used pads or diapers which introduced a monetary cost in addition to time and soap used to wash pieces of cloth.

The use of strict hygiene to conceal signs of their illness could be compared to Erving Goffman's concept of passing disability. To cope, survivors 'stayed alone' or with their children after the spouse left. It appears it is easier for the woman to manage an unmarried life given the existing hygiene challenges. Granted, it is not only women who have to bear with the hygiene challenges of vaginal fistula. Practical aspects like a shared sleeping arrangement with the spouse pose dilemmas to the women. This excerpt best describes the hygiene concerns of a woman who shared the bed with her husband.

Sometimes you are sleeping because you are tired you wake up to the fact the place you are sleeping is wet and even on his side he is also wet. You know that water, the urine is usually warm and before you feel the cold now when I am to the realization you are stressed and your stomach gets cold [giggles]. Imagine you

wake up and change the sheets you see that person has really been patient with you and that is no joke. You know that time we used to wash the sheets on a daily basis [...] then people see that you have hang the beddings and they wonder, 'they do not have a child what is the problem?'. (034-3F, 26 years, No child, Trans-Nzoia)

Psychologically, women believed they would get well and were encouraged by others. Further, those who heard testimony of others who have healed were encouraged to try treatment. A participant heard that there was a cure immediately she developed fistula illness; she says this helped her a lot.

Economically, some participants ran small agricultural businesses; cutting and selling firewood; working in a tea plantation; and selling vegetables in the marketplace. Others worked as house helps. Throughout the self/ other employed, the women had to negotiate with employer [025_01] or find comfort zones within their working environment to cope with and conceal the symptoms of the illness. For some women, they did not participate in any such economic activities, perhaps to avoid social contact and owing to the difficulty their condition presented them. Often, the symptoms of vaginal fistula made it impossible for them to participate in any meaningful economic venture. Economic sphere, some participants got work / jobs to do after developing VVF to sustain themselves. They navigated working situations by explaining to their potential employer their illness in advance of employment such as 015_01 who was aged 27years at the time of the current surgery. Others simply ignored the customers concerns as in the case of 009_01, who was cutting wood for sale. Notably, those who 'stayed at home' to cope with the illness were isolated socially and avoided people.

Social support systems to cope with fistula illness

Participants talked about support around the time of crisis, and recognition and disclosure of fistula illness symptoms. Women received varied forms of support: psychological encouragement, material support, advice on where to seek treatment and often, living

expenses. Some women were supported by their husband, but others were separated from their husband and had to rely on support from their natal family. Other support was from friends of the patient. Not so often, a form of support was offered by the teachers in a school where a participant lived. These last two are parts of the larger community support to the patient. Invariably, the presence or absence of social support modified the women's ability to cope with living with fistula illness.

Spousal support

Some spouses had been supportive to the woman during her illness. For instance, a participant who was stayed in their marriage attributed this to her spouse being supportive.

This quote illuminates the usefulness of spousal support to an obstetric fistula patient:

I see that he does not despise me. You know there are men who when they know that their wives have a problem, they leave you, you know, my husband has never left me even for a day. He has taken it normal. (005_2, 36years, 2 children, Kiambu)

A typical fistula patient who had received full support from their husband does not have to deal with devastating emotional and socioeconomic consequences of separation. Further, they may receive moral encouragement from the spouse to seek treatment as this following quote illustrates:

On the seventh month, I saw that the problem was still continuing. I told my husband about this and that is when he advised me to start coming for check-up. [...]. I did not see any bad feelings in him. We just continued living as usual except that he was always encouraging me to come to the clinic often so that I can get help. You know, sitting at home does not help; it is only in the hospital that you can get help. It is by coming to the clinic that God opened a way for us to find help. (012-3, 28 years, 4 children, Migori)

However, most women had to rely on natal family support, especially if they are shunned by their husband and their marital family. Others yet depended on their children to sustain them later in life.

I now see that the change is not good, the change is different. I told my father I went home and told my father, father where I live there is no help I stayed as if I

did not have a husband. I went home and I finished 10 years and when I went I lived with my father and mother. I now stayed with my father and when he called him [husband] he refused. I just left with my children, a girl and a boy and I lived with them and it was my father who was taking them to school. [...] I left because my husband refused me and so I went home and I just told my father and mother. They were there but now they are not there. [...] The one whose problems I had? He stayed at [his] home, he refused me completely. (003_1, 62 years, 2 children, Busia)

Coping within school environment

Some girls who developed fistula illness did so while in school. They then had to negotiate the social context of the school environment, with or without support of teachers and peers. In addition to isolation, feelings of shame and stigma, the girls have to cope with hygiene issues like having to change clothes and wash often, frequently visiting the toilet between lessons. The girls also have to take time off school to get treatment for obstetric fistula further disrupting their learning. This excerpt from a girl whose fistula occurred in her final year in primary school when she gave birth best captures the disrupted learning caused by pregnancy and obstetric fistula:

When I went back [to school] they [teachers] told me not to worry because urine was coming out. 'First go home and you get better and then when you are better you shall come back to school'. They told me not to think that they had discriminated me because they had told me to go home, I told them, no. They told me when I go back in July I would just go to do my exams I told them that it was okay. (027_1, 19 years, no child, Nandi)

The hygiene problems caused to girls in school are glaring because they are expected within the confines a school program. For instance, going to stay in school during the day, the chance to retreat and avoid people was not available to the girls. They had to endure the challenging social environment within school. A participant who had rectovaginal fistula was frustrated because despite her efforts at bathing, her peers always told her she smelt. She explained her difficult school life:

It is a day school. When I was in form one, no standard eight. You know I was using napkins, I just stayed like that. Students started telling me "Ezna you are smelling stool." I started wondering now me, even when I take a bath at home they still tell me I smell. Until I finished class eight and did my exams they still isolated me. I would just sit alone. I went to form one and students would still

tell me that. I would just isolate myself and even in class I would just sit behind alone. Even outside I would sit alone. One day when I was in form two, I started telling some girls about my problem then they started being close to me. [...] You know it is like whenever I felt like going to the toilet, it would just flow. One day it happened in class and all the students ran away from me. From that day I would bring napkins, pieces of cloth and nap myself. Every time I would go to the toilet and throw the dirty one and put on another one, then I started being clean a little bit. When it reached 4pm I would start smelling bad. (032_3, 17 years, 1 child, Kisii)

Girls with obstetric fistula missed opportunities in school, concentrating on cleanliness and hiding the symptoms, and they felt less capable of handling better learning environments like opportunity to stay in a boarding school. Often, they have to change schools to avoid previous bad experiences. The difficulty faced by girls who suffering from obstetric fistula whilst in school is best captured by the participant below. In form two, she changed schools from boarding to day school. And in form three she had to leave the school in Kisii to attend the fistula camp held at KNH.

It's stress... You know sometimes all my thoughts all [laughs] are on urine. I ask myself now this water, starts when I start walking in school, sometimes it trickles down my legs and am ashamed. And I cannot tell her because she will go and tell the others, so when she tells me lets go outside, I say, just go am coming. When she goes I take a pamper [diapers] from my locker and I go to the toilet and I change and she cannot know that I have a problem. Only one teacher knows. [...] They told me to do well so that I go to boarding school [laughs] so they had to fulfil that promise. But I told that teacher that I don't see managing life by boarding, so she asked me, why, I was unable to answer her because I was just crying. So I ask myself if I tell her, she will start questioning me a lot. I told her, let me just go to a day school. (061_2, 18 years, no child, Nairobi)

Obstetric fistula illness is not only disruptive to girls learning as it takes them away from school to they seek treatment. In addition, the shame they have to endure, isolation and constant hygiene issues is at the core of suffering. It seems the school environment is one of the spaces within which support to fistula patients can be offered and treatment

Family coping

The fistula illness inadvertently affects the family members, her siblings, spouse and her children. One of the family members interviewed was a daughter to a woman who had

undergone fistula repair surgery. Her mother had separated with her father during the illness and they lived at their natal grandmother's homestead. As an adult, she in turn was supporting her mother to recover from fistula illness. Even in marriage, the daughter is not settled and considers going back home to care for her mother. The isolation and gossip at church get to her and affect her negatively. It seems as though the burden of fistula illness is also carried by the family members with psychological suffering. She narrated to us her experience of her mother's illness:

I hadn't known the problem and I began understanding about the illness when I was in class 7. I knew that mother had a problem and I may be understood that's her nature. But then coming to understand that she has a certain illness and reaching to the point of it affecting me it was after realizing when she goes to the church the odour would bother her and the people seated next to her would bother her you know when you are brought up in a certain situation it reaches some point you get used to it. It seems normal to you but then it seems abnormal to someone else and it is terrifying. Now when I came to realize people talk about her it was when people were travelling and if they were having a sleep over they wouldn't accept her and then when they do not take her along they still not talk about it and maybe when there are gossips that is when you would find someone talking. (KII 003_1 Daughter)

The spouse to a woman living with fistula often has to put up with gossip and negative remarks about their wife. They also have to rely on his sole source of income because she cannot work in her condition, besides the little farming they do in their homestead. Their social interactions are quite limited owing to a restricted social network, and it has affected the spouse too. A man explained how his wife's illness has affected him:

Even when I go somewhere near people they start to say, 'that person stays with a woman whom urine comes out and the stool comes out'. Now I just endure in everything. All that is said I endure, because I cannot send her away or abandon her. I have accepted to stay with her just the way she is. (KII 006_1 Spouse)

This finding shows that fistula does not only affect the woman, but has potential negative ramifications for family members including the husband and the children.

4.5 Summary

Women living with fistula are young, illiterate or with low levels of education. They are in their youth and at the start of their reproductive careers with about a third having no surviving child. Women living with fistula endure moral properties of living with fistula, psychological distress, suffering, isolation and stigma. Socially, the women experience poor sexual relations that often lead to separation and divorce. To cope with obstetric fistula, women relied on family and other social support systems at the macro level. At individual level, women restricted intake of water, hid from the public and constantly washed clothes and bathed to keep clean. They undergo multiple surgeries in an attempt to treat the illness with about a third having had previous unsuccessful surgery. Although fistula illness is curable through surgery, many women spent decades living with the condition due to individual factors such as lack of information and awareness concerning the illness, lack of money and fear of disclosure. The health system factors include lack of diagnosis and referral of fistula patients to facilities that can treat fistula, and lack of facilities that can treat fistula. The health seeking behaviour of fistula patients is presented in Chapter 5.

CHAPTER 5: HEALTH SEEKING AND TREATMENT PATHWAYS

In this section I argue that the onset of fistula illness' symptoms is a major crisis that triggers help seeking to regain normalcy. Although there are many symptoms of fistula, the women recognise most easily the urine and stool incontinence. The crisis is not only recognized by the participant but close family members. Two core issues that drive health seeking by women are hygiene concerns and desire to regain normal bowel control and reproductive function. There are enablers and disablers to treatment of fistula patients at the individual and health system level.

A typical storyline of health seeking behaviour during fistula illness depicted in my study is that of sequential pathways with initial many visits to hospital getting few surgeries. Fistula therefore becomes a chronic illness that women have to live with. Living with fistula entails moral properties of suffering with generally long pathway to care that did not always guarantee access to care. There is a deviation from normal and women strive to regain normalcy in their physical health, social acceptability, marriage and economic independence.

Typical narrative of health seeking for a fistula patient entails sequential pathways where she moves from place to place, person to person seeking treatment. Initially, many visits to hospital get few surgeries, owing to either lack of facility at the hospital or high cost of the surgery. Fistula therefore becomes a chronic illness that women have to live with, attempting multiple times to at regaining normalcy.

Women's realization of symptoms of both rectovaginal and vesicovaginal fistula sets off an account of a convoluted pathway that did not always guarantee access to care. For instance, a typical narrative starts with symptoms around childbirth:

When they pulled the child [AVD] that day water [urine] started to come out together with faeces. Now, the faeces were coming out as if it is watery. And the urine! I sit like this when I get up... Even if you have eaten *ndengu* [green peas] it comes out that

way. When I drink tea it pours like that. And they come out together. (018_1, 25 years, no children, Siaya)

What follows however, for this and many other similar stories is daunting. They meet a health system unresponsive to needs of women with few fistula experts, missed diagnosis, lack of pertinent information and logistical support. Further, the women themselves may not be motivated to undergo surgery, fear of death and poverty. Lack of social support, divorce and separation add to the other stressors in the process of health seeking. Few women experience the ideal enablers of healing and regaining normalcy, namely, correct information through radio, access and linkages to care through mobile phones, and most vital surgical facility and expertise at a cost they can afford.

Women's narratives concerning their health seeking behaviour are presented organised around broad emergent themes namely i) pathway to treatment, ii) health seeking behaviour and iii) treatment for fistula illness. These categories are further described in detail the smaller subthemes whose properties made up the core category.

5.1 Pathways to treatment

This chapter describes the places and people the participant contacted to seek treatment for obstetric fistula illness. Narration of the various channels the participants took in seeking healing includes formal and informal networks; hospitals, traditional medicine, home remedy or I just stayed home. Generally, the pathways seem linear with women moving from hospital to home to another hospital. Several months to years elapse between one hospital visit and the next. It is also common for one woman to have multiple corrective surgeries for the illness.

Women identify two hindrances to their seeking treatment, namely, lack of money to pay for surgery or procedures and failure to find a hospital where they treat vaginal fistula. These two conditions persisted until a woman encountered a free VVF camp or centre.

Notably, women travelled far distances whilst seeking treatment but this difficulty was surpassed by the hope that they would get healed once they accessed care and treatment at the chosen hospital.

Participants sought treatment because of the bad smell and hygiene issues related to the illness and because they had been referred.

What made me go there was the smell. The smell was too much that at times I could also personally smell it. I decided to go and seek for assistance to see whether I could be assisted. They only gave me the drugs to clean and wash away the smell. The urine continued leaking. [...] Even if it could have been far away, I still would have gone because I wanted to get well. I was sick. (005_1, 32 years, 1 child, Marakwet)

Others persevered hoping the symptoms would remit but when this did not occur is when they sought treatment. However they came to be treated because felt pain and were referred to the fistula repair hospital.

I went home. I stayed with my problem. For almost eight years I have been using pads. That is day and night. Last month I started experiencing some pain in the pelvis. That was around April. I went to Mbagathi. When I went there I was X-rayed. Then they referred me to the MCH Section just within Mbagathi. I went there on Tuesday because their clinics are normally on Tuesdays. When I met the doctor there, he told me that they could not assist me but they could only refer me to KNH Clinic 66. (001_2, 31 years, 1 child, Nairobi)

There is a long period of time staying home living with fistula illness as presented in the previous section. Two typical scenarios present: women who, upon noticing the symptoms, stayed home as the first reaction or having attempted seeking help but were not successful, had resigned to the fate of living with the condition. What does it mean to stay home with the illness? The phrase, 'I just stayed home' has deeper meaning. Yet it seem this was always a fall back plan in the face of a health care system that offered little in terms of treating fistula patients. Those who sought treatment in hospital were treated, albeit with a lot of referrals and 'to come again' visits, or had to content with information that this illness was not treatable elsewhere. Then they stayed home. The staying home with fistula

is a suffering experience as presented in the previous chapter, living with fistula. The participants stay because of having been referred, but also because they have no money to do some required tests. One participant who reported financial challenges explained her situation:

I stayed. I did not seek any treatment, I just saw even here who will go and tell a problem like this one. And I stayed. And then, one time I don't know what year it was. I heard there was treatment like that one I just heard it was called I don't know" RR". I heard it was called "RVF": I heard on the radio. Now it was being done in Kabarnet. And I could not go. I had a little financial problem. I never went, I saw let me stay may be there is a time it will be done elsewhere, another place. Another time also another year I heard it was in Kisii, the same thing. (016_1, 48years, 4 children, Uasin Gishu)

Some participants lacked transport to go to the next health facility they were referred for treatment. The referring facility could be far off or at times within the same county. A participant who lacked transport to get the referred facility explained:

Sister told me 'here we have no help, you have defeated us. I will help you, I will write for you go to Busia'. Now she wrote for me. She told me 'If you have transport you go to Busia immediately they go see where that flesh is coming from. And that urine also, what's wrong, the leg what's wrong'. Now when they had written for me, I went back to the house. I looked at the transport cost; you know the way for us to get this is hard. (021_1, 35years, 6 children, Busia)

Most women seeking treatment had to travel using public transport and the hygiene challenges were more glaring. A woman suffering from fistula goes to an average five different hospitals. She has to travel using public means with faecal and urine incontinence; yet earlier she has described how even her neighbours would not stand the condition.

Nevertheless, most participants went back to hospital as a popular treatment choice resulting in as many women going back, up to 9 hospital visits to the current surgery. There seems to be a systematic fail in the health care system to offer them surgery. The hospital seems to be the key disperser to other health care options in treatment pathways. Although from the other alternatives women come back to hospital, they are almost always

persuaded to go back there having not healed within the health system. A quote that illustrates this point is taken from an interview with a woman who had lived with fistula for 33 years and obtained her first surgery at her seventh visit to hospital. By the time of interview, she had a total of four corrective surgeries in the previous five years.

When I got this treatment in Kakamega is when I received the operation [Caeserean Section]. So they told me that it was dirt. That is in the stomach and it will just be over. When I went back home it continued. That doctor told me to go back there and I went back there. They found out that it was still continuing and they gave me another appointment. So when I went for that appointment, there was no doctor. And they gave me another appointment. I went and they told me, 'you could have been operated on in the theatre but there is no water. Go back, and they gave me another appointment. I went back on that date, and so they told me there was no cotton wool to do that job. I went back home. They gave me another appointment. So I went and they put me in the ward. I stayed in the ward for two weeks. Then they said, 'when we examine you, we see that you are destroyed badly, and we cannot'. So there they said the truth when I had gone to the hospital around five times. 'So now I will go back home?' Mmm [yes]. 'Without treatment?'. 'Without treatment'. I went back home. I went to mission hospital and they told me 'go back to Kakamega, we don't treat people who are like this'. I said I have gone many times to Kakamega and they shocked me and they told me this last time that they cannot; now again I am to go there? So I went back home and stayed. (036_1F, 57years, 1 child, Kakamega)

The multiple hospital visits are not unique to the women who have lived with fistula for decades. Even those women who had the illness for just a few months or years went to hospital many times. Granted, an elective surgical procedure may require booking and an extra visit to the hospital. But in most cases, women were not booked because there is no surgeon for fistula illness, albeit they were not privy of this truth. They kept going back to hospitals to try and see if they can find this vital service, but the service was not available.

Notably, some participants who underwent surgery went back to hospital for as yet another surgery due to unsuccessful surgery. Multiple surgeries made the treatment seeking pathway longer, with numerous contacts with the formal system interspersed with home remedies, seeking prayer and divination or just staying home.

Most women seeking treatment had to travel using public transport and the hygiene challenges were more glaring. A woman suffering from fistula goes to an average five different hospitals. She has to travel using public means with faecal and urine incontinence; yet earlier she has described how even her neighbours would not stand the condition. Granted, her condition may not be acutely life threatening, however, the situation is direly 'urgent' for her. What would reduce this stress is a more accommodating form of transport and access to hygiene kits. Ultimately, she needs efficient and prompt surgery, which can be realised through the formal health care system. Furthermore, even though eventually the surgery is 'free', multiple visits will cost her money which may be a challenge to her as seen in some participants' narratives presented below. Experts have stated that the desirable ideal is when one visit and one surgery lead to healing, which is not the case demonstrated here.

The key finding in women's treatment pathways is that the health system failure to diagnose and treat fistula leads to their dispersion from hospital to other alternative care providers such as healers or staying home or seeking prayer as the sequential steps in their health seeking trajectories. These trajectories are lengthened in multiple surgeries and referrals, and women further the timing by adding many other 'visit points' at the alternative providers.

These components of the treatment pathway of fistula patients deserve close scrutiny as therein is the crux of understanding what entails the illness behaviour of the participants. The elicited points of care seeking are the hospital, home remedy or just staying home as the first response to managing their symptoms. The next elicited components are those of seeking diviners/ traditional healers for traditional medicine; seeking the care of private health care providers, prayer and seeking out the help of Non-Governmental Organisations. It is these seven components that constitute the complete range of persons

whose support is sought by women who suffer obstetric fistula and may serve as intervention points in offering women prompt care.

Whilst seeking care, women often get the help of and consult with to get information from their close family member or friend or spouse, and ultimately from health care providers. The most strategically placed and therefore more likely to be consulted are the nurses, midwives and doctors in the hospital in which the woman delivered the baby and subsequently developed the fistula. They also have an opportunity to screen women for fistulae, especially when patient history is familiar with narratives of difficult labour and prolonged hours of unskilled labour and delivery, when the women needed assisted vaginal delivery or caesarean section, and had poor labour outcomes as presented in section 4.1.

This offers very opportune moments to the labour and delivery healthcare team to correctly diagnose and treat or refer for treatment women with freshly developed obstetric fistulae. In this study, while it is true that four women had surgery in the immediate period, the rest were not so lucky and had to endure the stresses of fistula presented afore. This finding has implication on training, equipping facilities and labour and delivery service provision that is more prompt in responding to the needs of women who develop fistula.

Kenya has a few fistula surgeons and few nurse midwives trained in fistula care. The basic nursing and syllabus also has components of fistula care training. But whether this skill is being practised is not evident in the narratives presented here. It could be that this training is not being practised or was only recently incorporated into the system when the participants already were home living with the fistula. It would add value to the current care of fistula survivors if a training needs assessment is conducted in those health care providers working in maternal health in Kenya. Moreover, the facilities able to offer dedicated surgical facilities for fistula are few.

Referral during VVF Treatment

During treatment for obstetric fistula, women were referred from one health facility to the other, and at times had to be rebooked appointments in the same facility for various reasons. These appointments and referrals increased the number of times they had to visit a hospital for treatment and partly explains the nature of their treatment pathways. For instance, 006-2 arrived at the last few days of a free medical camp and was asked to come back in the later due to sheer number of women who had been booked for operation. This introduced a cost and economic burden to her spouse as demonstrated in this excerpt:

I was seen by the doctor. He said its emergency. So the time he booked me I was told to come the following day. Coming the following day, I entered they told me come the hours of lunch time. Coming lunch time they told me no we won't do it on you today go and come back tomorrow. Now you see this is a way of going and coming back. It reached somewhere my husband started quarrelling me, this is what things which I am not seeing its usefulness because you have been wasting money on the way going and coming. Do you know you are wasting my money? Me I got angry there and decided to stay at home with that problem. (006_2, 32 years, 5 children, Machakos)

The length of time is even greater when the participants consult in health care facilities that may not have capacity to diagnose or properly refer fistula cases. For a participant whose pathway took her ten years to obtain proper diagnosis and treatment, ultimately at a fistula camp, she started off at a private health facility which was not necessarily equipped and skilled in diagnosis and treatment for fistula. The attempted surgery at this private facility did not correct her fistula. She remarked:

I had stayed for long, you know that problem of going to tell doctors and they don't know what you are telling them? I stayed [...] for like 10 years, 10 years. [...] It is private. But I went to theatre. I don't know what they did to me. There is no change I saw. (013_2, 48years)

We asked another participant the reasons that made her to live with the fistula illness for seven years. The reasons included lacking information on where such condition can be treated and the hope that the participants hope that would heal spontaneously. In addition to the total time count, this participant was referred upon diagnosis, adding a count to their total hospital visit.

I didn't know where someone could go to the hospital and I didn't know about fistula, I didn't know whether I had fistula I just thought that it was my bladder that had a problem and maybe with time it would be okay. I just stayed with it and I didn't know whether there was a place I could go and it gets repaired and it becomes okay. [...]. I just struggled with it and now in 2013 I started feeling a lot of pain over here and so I went to Mbagathi hospital and they took an X-ray and they saw that I had a problem and they then referred me there [...] One female doctor tested me, she told to get up on the bed and she inserted her arm inside and she found that I had urine inside there, I was wet and I wasn't supposed to be wet. She told me that wherever she was going to send me I was going to get help, I was supposed to go to Kenyatta [KNH] (001_2F, 31years, 1 child, Nairobi)

Cost of surgery

The cost charged by the hospital was a limiting factor especially for participants who sought treatment at private or mission hospitals. The camps being free attracted a lot more women. This contributed to the long time spent with illness and multiple hospital visits. Often, once a woman was seen at a facility that could treat the illness, they could not raise money to pay for services. They would then stay with their problem. Locating a fistula repair centre is not a guarantee for surgery, except in centres where the surgery is offered free of charge.

The participants' perception of inability to afford also keeps women away. For instance, this participant explains why she did not pursue treatment and lived with the condition for 2 years:

When I went to ask at the dispensary that is usually at our place they told me that the treatment is usually very expensive. When they told me that I knew I would not be able to afford treatment. I now saw it was better if I learned on how to live with it until when I heard about here and that it was free and I decided that I should come. (020_2, 34years, 2 children, Kiambu)

But real challenges at payment rather than perception of cost were the greatest hindrance to participants accessing screening, referral and care as explained by a key informant:

We were forced to just stay like that because we did not have money. Ah, we stayed like that and my wife now had that problem. Then we are used to that her problem. I myself as her husband am used to it. Although now for children, it became hard to get a baby. I tried and went to Kenyatta. They said they wanted money for the X-ray. I did not have the three thousand shillings. I went back and

stayed even with those letters. Then later I was lucky to meet a certain lady. She told me she would take me somewhere where my wife would get help. When she went there, she came from there with problem having doubled. It was twice now. It was urine but now it was with diarrhoea, stool now was coming out. Mmm, even that condition, I am used to it because we just stay. We have seen that it is how the world is. (KII 006_1 Husband, Kakamega)

Women's lack of knowledge of the condition, lack of capacity of health facilities to conduct fistula surgery, monetary and logistical cost of treatment services resulted in participants multiple visits to hospital and a long stay with fistula illness. Other women were afraid of surgery, and this in addition to the aforementioned reasons kept away from treatment. For instance, 030-3 had been to more than 5 hospitals in thirty years. She experienced fear of surgery, especially in a hospital she had underwent an unsuccessful surgery before. Lack of money and several unsuccessful surgeries interplayed to prolong her health seeking pathway. She explained:

They examined me and said my bladder was destroyed. They told me to go and eat well for three months and then I go there so that they can try treating me. So when I saw that the money required at Kindu Hospital was a lot, I went to Russia hospital. I was treated there but I did not heal at all. The urine continued coming out. They then told me to go back there but I was afraid. I went to another hospital in Kiambu called Nazareth hospital. I was treated there and was not healed. So since then I have stayed in the house; I don't go anywhere but tolerate the problem since that '79 until now, 2013. That's when I heard the radio advertising that there will be a doctor here who will come and help the women who continue to have urine coming out. That's when I tried and came here and I have been treated. (030_3, 53years, 1 child, Kisii)

Traditional medicine

Participants pathway of how, when and where they sought treatment is interwoven with discourses of religion and prayer, traditional medicine and home remedy besides health facilities and private health care providers. Outside of the formal healthcare system, the individual with the help of friends or family seeks for and obtains what in their perception has promise to remedy their condition of obstetric fistula.

This point is best illustrated by a participant who lived with fistula illness for five years before her first surgery. In seven hospital visits, she had undergone reparative surgery four times. The visits to the diviner and healer are her second and third health pathway choices, after failing to obtain treatment at her first contact with the hospital. She explained:

I stayed and I was now saying the way this illness has started on me like this, others were telling me that with this illness I shall just take traditional medicine it shall end. I took the medicines there wasn't anything. I was taken to the witch doctor there wasn't anything. I said "eey" maybe this is my death. I stayed until 2009. When 2009 came because my stomach had not been washed it had dirt and now the stomach started swelling. (009_2, 22 years, No children, Homabay)

At times, the consultation with diviners goes on alongside hospital treatment especially at the onset of illness. A participant's narration of thoughts of witchcraft and consulting a medicine man present:

I thought I had been bewitched until my aunt came and told me that I had been really been bewitched and that this wasn't an illness. She came and gave me, she took the *leso* (wrapper) I was using and gave me the one that belonged to her and she took it to the witchdoctor but she didn't get any answers. She never got answers. Up to today she has never told me what had happened for me to be like that. She didn't tell me what happened at the witch doctors place, I was discharged before she came to report back to me. (025_1, 31 years, No child, Baringo)

Religious discourse and prayer

Just like when they were living with fistula and had a hope in God for healing, the women also sought active prayer over their condition. For some participants, the church provided a form of social support especially if the woman was isolated from general society. It also was also one of the social settings within which stigma were enacted as seen in this excerpt:

I went and was prayed for, my church is spiritual. [...] but then the urine hadn't stopped, it hcontinued. Let them now gossip! 'She thought that she had healed and brought a man inside her.' but then I and my God are the only ones who know. [...] And even if there is trouble I put all that to God because you cannot lack and I think God's people are the ones who go through many trials, the devil tries you so that you can insult God but then I cannot insult God because he has brought me from far". (010_2F, 42years, 4 children, Nakuru)

Participants as wells as family members referred to Gods healing. For instance, a spouse to participant observed that it was God's help led them to a hospital that offers treatment:

I have no fear other than how she was sick, I did not know if she would be healed. But there is God. I have gone with her till Webuye. They said here at Webuye, there is no treatment. If you want to get treatment, Just rush go to Eldoret [...] I was also very afraid and said, now where will I get money to go to Eldoret, Moi Referral. But God had planned that we come in to that your hospital, Gynocare

fistula hospital. We went in there and I was just praying, 'God help me'. I didn't know if she would be healed but behold God remained being God. (KII 029_1 Spouse, Bungoma)

The religious discourse seems to be a source of hope for the women especially when they talk about healing. Many instances of women explaining how they coped with illness result in a focus on God for healing, and when people prayed for them, it was for them to get means with which to be treated at a hospital.

5.2 Enablers of Health seeking behaviour

The way in which patients can obtain information about available services and channels through which they contact or be contacted by the health provider serve to ease their access to treatment. Participants mainly heard about fistula repair camps through radio advertisements, a method utilised by all the three repair centres in announcing the availability of their services. A few however were referred by a health provider or were directed to the facilities by family or friends who were knowledgeable about the existence of the facility. The use of mobile phone communication aided many women to access treatment centres and health care providers in follow-up and subsequent surgeries. These components of healthcare for women with fistula are an example of how common affordable technology can be used to link women with care. Family and friends represent the larger community who, aware of the illness, could assist many women to get treatment.

Radio advertisements

All three hospitals utilised radio advertisements to inform women of available free treatment services. The women heard these advertisements by themselves or were in turn informed by members of the family, friends or even healthcare providers they were in contact with. A participant described how she heard of the fistula repair camp at KNH but was prompted to go for treatment by her son. She had lived with fistula for 30 years and this was her first surgery, and second visit to hospital concerning her illness.

We heard about it sometimes back on the radio but I did not take it as something serious but later on there was a doctor in Nairobi. Eeh, and my last born child is there in Nairobi. It is him who spoke to that lady and then he called me towards the end of May. Eeh, he told me that 'I have heard about treatment here in Nairobi. A friend of mine who is a doctor has told me that they treat people with a problem like yours so I want you to come. Leave home on 26th and you will get here in Nairobi on 27th then on 28th I will take you to Kenyatta'. So it is his friend who works there at the hospital. She was called *** and she also came at the hospital to greet me. (033_2F, 54 years, 3 children, Siaya)

Friends to women with fistula not only provide psychological support and social interactions but they can also provide information about fistula surgery and an encouragement to seek treatment. For instance, a participant was informed of this radio advertisement by her friends and subsequently received treatment.

It was being advertised at the radio that and some women were telling me that why don't you go there so that you can be treated? To be treated. So I said aha, it will come a time that I will just go. I will go; I will not refuse to go (033_1, 57 years, 6 children, Busia)

Health care providers are in unique positions given they are consulted by women with this illness, and they are likely to know when the next free repair surgeries are available. They provide a key referral point for women with fistula illness, with those working closer to the communities being able to link women with care. A participant who was contacted by a healthcare provider who had heard of the fistula repair services explained:

Then Sister **** from Mumias said... First I heard advertisements from the radio saying that the women who got problems, they are supposed to go to Eldoret so that they can be treated. So they prepared a day, I cannot recall the day but it was on Thursday, they called us and we went to Chwele and they conducted a scan on us and then they told us the date that we would go to Eldoret. I came here in 2011 to be operated on for the fourth time. (037_1, 50 years, No child, Bungoma)

When knowledge about where treatment can be obtained is made available to women with fistula and the general public, it is likely to be used by women to seek treatment. The knowledge provided in this three hospitals' advertisements was that the surgery is free, conducted by experts in fistula care and the location in time and place. This removed cost of payment to women who previously found it expensive, and those who had not found a facility that could offer this treatment accessed this care.

Using mobile phones to access VVF care

Gynocare Fistula centre partners with community based organisation and regional representatives in western Kenya to link women with the centre. Some of the regional representatives have been cured from vaginal fistula and run awareness campaigns in the region. Central to this link is use of the mobile phone to connect with women with fistula. The phone becomes a core of contact between the representatives, the centre and the patient. Further, it is used for follow-up after surgery. A participant treated at Gynocare described how her mobile phone assisted her in accessing care:

She told me that there was a hospital called Gynocare, after that first [operation] failed. She told me there was a hospital called Gynocare and if you go there and talk them they will assist you. So she gave the phone number of one of the ladies here called **** and when I called her she told me that she was in the field and then she send me a phone number of somebody else who works here ****, and when I called him and explained to him about my problem he told me that at the moment that all the beds were occupied but he was going to see on how they would assist me. So we stayed for a while and I then called him so as to explain to him and he then told me to go and see on how they were going to assist me. When I arrived he sent the madam called **** when I had reached at the reception and then that lady brought me here where I met the doctor on that day and he told me this was done to me I had to be sewed.(022_1, 24 years, 1 child, Kakamega)

The mobile phone becomes an important part of care especially when there is poor road network and women have to travel long distances to reach the health facility. For instance, the cost of travel from one end of West Pokot to Eldoret meant that it was most efficient if the centre was contacted prior to this essential travel. The women either used their phones, those belonging to family members, or in other remote areas, the local chief's phone.

We stayed and we said that we were supposed to go again to Kapenguria. When we arrived at Kapenguria they told us to go to Sentinelles's Hospital and we then went there. We stayed there and they told us to go there and then a day would come when we would call you over the phone so we went home to wait for the phone call. They called us and now I came accompanied by my brother when we arrived at Sentinelles we slept there and the following day we came with **** here. (024_1, 17 years, No child, West Pokot)

In other instances, these contacts were provided by the facility that diagnosed fistula illness, in addition to referring the woman to a facility where she could obtain treatment

for obstetric fistula. This interlinked referral and networking by facilities was most useful to this patient who was diagnosed immediately after childbirth and referred. Consequently, she lived with fistula only for less than a year as opposed to the typical narrative of women who live with fistula for decades.

They also gave us a phone number and told us to call that sister on this number she would help us, we went with that number and when we reached home we called it. It is sister *****, we called and I explain to her how I contracted this problem and then she said she would come to visit us at home, she came and visited us, she booked me and she told us that we would wait when she called us that is when the patient would go to Eldoret and she then called and I now came here. (026_1, 18 years, No child, Busia)

In the event a woman with fistula leaves her contacts with the focal person in the health facility, they may be contacted in time for the next available camp as explained by a participant at Kisii Hospital:

I was told once I get well I should go back where I had been treated so that they could treat me. I stayed and then came back. When I came the Sister told me to go back home and come back the following year. She said that in between September and October they would contact me. I took the phone numbers of Sister ***** and the other Sister. We used to talk often with Sister *****. They gave me the numbers. When I went home and stayed, she told me the treatment would be on ... I actually came here two times. I even went back ... they told me to come back in 2013 on September 28. (010_3, 51 years, 1 child, Kisii)

The essential role that mobile telephones play in linking up women with care is sustainable given all women in the study had access to a phone. The mobile phone also provided a key follow up contact which we used in booking appointments during our community follow up phase of the study. There may be limitations related to changed phone numbers and address, but this remains a viable model that may be used to strengthen communication between patients and healthcare providers.

5.3 Experience and perception of fistula treatment services

The study sought to establish women's experience of being screened and treated for obstetric fistula illness in the formal health system. Through these experiences we get a glimpse of the current fistula care services in Kenya from the clients' perspective.

Screening and treatment

The study sought to establish women's experience of being screened and treated for obstetric fistula illness. Through these experiences we get a glimpse of the current fistula care services in Kenya from the clients' perspective. Granted it is a useful service that often sets off the process healing and return to normalcy for many women as discussed in the following chapter. However, most women do not understand why they have to be examined several occasions, and conduct tests. This disappointment is expressed by those who eventually did not undergo surgery at the point of screening as in the excerpt below:

When I went to the theatre every single place I went for test would cost money and I went to the theatre and they took blood sample and also the stool and they tested. I was told to go to that door and so I went and I sat until it was time to go to the theatre and when I reached the theatre they put me on a bed so as to check where the "nini" came through. They now began to check and it was painful and they would put one leg on this side and the other on this side and hit properly. And then open up here and then you feel a lot of pain as they move some metal like this. You feel something cold touch you here and then they open, I now persevered and said even if it is painful they cannot pierce me and all I wanted is to get cured. To be treated and so I stayed and they bothered me until I saw blood come out. When it came out they gave me cotton so that I could wipe and I said 'what have this people done have they sown or have they torn, what have they done to me I felt pain and even sitting like this is hard. I came and sat down and then saw that the urine was still coming out and so I told the doctor why haven't I cured and why is it still coming out. Now why has it mixed with blood, what is the reason, he told me they hadn't repaired. He then said they wanted to see how they would treat it. I asked what they had found he told me that they would write me a letter for those who have knowhow. That is the experience you go to be treated from there and I felt that I was tired and I was given pills and wondered what was the use of the pills and they would have just told me we have prescribed you this pills so that you take and you will heal, why didn't they tell me, I left heavy hearted. (010_3F, 51 years, 1 child, Kisii)

Multiple surgeries

Some women underwent multiple surgeries to treat VVF. This meant that for that individual patient, they needed several instances of contact with a health facility during treatment and their pathway would be longer. Multiple surgeries present women with the challenge of having to 'live with fistula' after treatment. It usurps their hope of recovery and puts social pressure on them, especially from the spouse. It could be these surgeries

contribute to lowered expectations of recovery and heighten anxiety. More so, women who underwent multiple surgeries had to cope with more technical problems like having to live with a colostomy bag, a procedure that in itself necessitates multiple surgeries. Other complications of VVF like renal stones necessitate additional surgical operations. These complex procedures mean a longer hospital stay in addition to multiple surgeries and additional visits to the hospital. A narrative that best captures the complexity of multiple surgeries in fistula illness is that of 22 year old participant who had both VVF and RVF, having lived with fistula illness for 5 years before her first surgery, and in two years underwent four surgeries.

I was operated on, the first one [2011] was to correct the urine problem but it refused. The second one again they did it but on reaching the theatre they began and found they were passing the same way, the faeces and urine were passing the same way. Now they were required they put [a colostomy] because the faeces were passing on the birth canal. ... When 2012 reached I was again returned for an operation so that they can make the urine. Afterwards, I was still leaking so they told me now you are going to the big doctor in Kenyatta. They wrote for me a letter, now when I came here I was admitted and yesterday I went to the theatre. (009_2, 22 years, No children, Homabay)

Another participant as the first presented above, understood that her condition which involved both RVF and VVF required multiple surgeries that would be done at different times. Costs related to screening for her first surgery had been sponsored by her employer as she explains:

They told me that they were going to repair my stool then they would see whether they could repair the urine later. They told me to go back home and I was to come on a certain date I now went back and when I reached where that woman was she asked me how much money was required of me to pay I told her 6,000 and when she asked about the date I told her and that was still in 1999 I went back to the doctor and he told the day I was supposed to go. I went and I was admitted they then began repairing the urine they didn't repair the urine. They repaired me and I don't know whether I stayed for a week and I then saw that stool wasn't leaking without control and I was going to the toilet properly. (025_1, 31 years, No children, Baringo)

These participants reflect the long and torturous path that treatment could take in case RVF and VVF occur in the same patient at the same time. Women who had complex forms of

vaginal fistula with both conditions had more number of surgeries and hospital visits. Their treatment pathways are likely to be longer, and recovery, complex. It also involves alteration of ‘normal’ bowel function, for instance, urinary diversion.

Urinary diversion is however not only offered to women with RVF and VVF concurrence. Previous unsuccessful multiple surgeries in a participant were the reason this participant was offered urinary diversion. Although this procedure was not performed in her case, it is one of the surgical treatments available for fistula patients. She had her fourth stillbirth and developed VVF at age 25. By the time of participation she is 41 years old, and has had her fifth surgery having lived with fistula for 16 years.

The doctor told me, ‘this problem with you seems like your urine tract is worn and cannot transport the urine so we want to help you; we block those tracts so that they go to the side of faeces [urinary diversion]. There will be a white man who will come from America and he will help you’, so I said no problem. So they did scanning when I came back. (034_1, 41 years, No children, Busia)

Women appreciated whenever the symptoms of urinary and or faecal improved, they were however in distress if the symptoms continued. It seems it is not so much the quality of care offered but rather how the women perceive its outcome that they assess the care received. Besides the symptoms, women talk about their bodies in a new light after surgery. The cessation of symptoms means a certain freedom of movement and possible establishment of social roles such as visiting their kin. A participant who had lived with fistula illness for 20 years is aware of the freedom the surgery offers, the opportunity to visit her daughter. The second surgery in one year had regained her urinary continence and got her to declare ‘this is not my body’.

I feel very well. I have been treated. I have received very good care. I’m well now. I’m very happy. Even at night I was able to sleep. When I came from the theatre, I slept very well. I was not worried about the urine leaking. I also ate well. I really feel very happy in my heart. This is not my body. My body has really changed. At night I just sleep. I no longer have stress. When I was unwell I could not even go to my daughter’s house. Even when they have visitors, I cannot go there. I’m soaked in urine. Right now I feel very free. I’m very happy. I thank the Lord. The way He touched the white man to organize so that we can get free treatment. May the Lord

continue being with him. It is very good and I'm very happy. (010_3, 51 years, 1 child, Kisii)

Fistula repair centres recruitment approaches

Most women who attended the KNH and KL5H free camps heard about it over the radio. Those who attended Gynocare heard both from radio and were linked by regional representatives. Both centres followed up their participants on phone. KNH exclusively reached their participants through radio advertisements, though personalised follow up was not achieved as in the previous two sites. There are variations between the composite pathways for the specific recruitment site and between the Gynocare and other site pathways. One camp in Kisii was postponed and this would count as a HSB point in their narrative; on the other hand, Gynocare which has regional representatives links women directly to care instead of their being referred from point to point, shortening their pathway points.

However, it is important to clarify that the women moved along different hospitals and the hospital pathways do not imply the participant has had multiple contact with the particular fistula repair centre without surgery; on the contrary it means they have accessed here their most previous surgery and are simply narrating where they have been before they reached here. Here is an excerpt describing how a centre used regional representatives and mobile phones to link up fistula patients with reparative surgery.

She told me there was a hospital called Gynocare and if you go there and talk them they might assist you. So she gave the phone number of one of the ladies here called **** and when I called her she told me that she was in the field and then she send me a phone number of somebody else who works here, **** and when I called him and explained to him about my problem he told me that at the moment that all the beds were occupied but he was going to see on how they would assist me. So we stayed for a while and I then called him so as to explain to him and he then told me to go and see on how they were going to assist me. When I arrived he sent the madam called **** when I had reached at the reception and then that lady brought me here where I met the doctor on that day and he told me this was done to me I had to be sewed. (022_1, 24 years, 1 child, Kakamega)

At 24 years with one child, the participant took an ideal less than one year living with fistula before obtaining surgery that had now regained continence. This ideal short period of living with fistula was however an atypical negative case in the typology of fistula patients trajectories, the most representative itinerary being longer with deleterious experiences. Grounded theory however caters for accounting of such atypical cases in the discovery of substantive theory as discussed in chapter three.

5.4 Composite pathway of health seeking behaviour

Participants' individual narratives were read and a pathway constructed. An example of a typical health seeking pathway of a fistula patient is presented in figure 5.1 below. In this pathway, the participant has long episodes of staying home without any active remedies. This experience is best summed up in the living with fistula section 4.3. The participant also has several visits to the hospital before finally obtaining surgery. During the course of her illness, she is divorced and leaves to fend for her 7 children. The participant depicted here is among the atypical of women who have surviving children from fistula illness. However, her trajectory does not include other steps seen in the composite pathway of alternative medicine or manage their illnesses through prayer and other avenues. These factors are best illustrated in a common pathway for participants presented in figure 5.2 below.

A typical health seeking behavior pathway of a fistula patient

Age at recruitment: 40 years
 Education: Primary 5-8
 Surviving children: 7

Age at onset of fistula: 35 years
 Marital status: Divorced
 County: Nakuru, Kuresoi

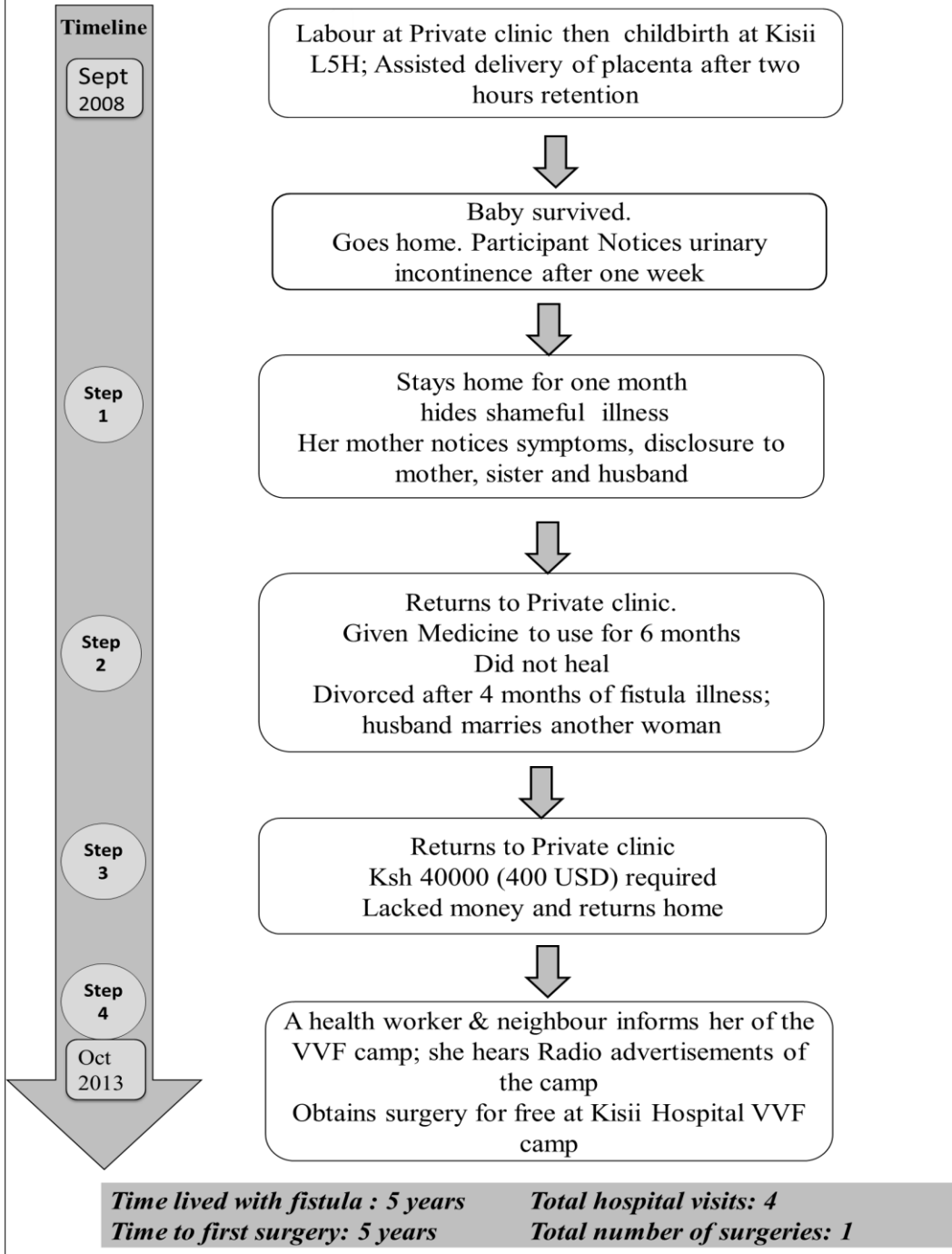


Figure 5.1: Typical health seeking behaviour pathway of fistula patients

A composite pathway emerging from all participants' narratives was then generated and the model drawn as illustrated in Figure 5.2. The model was tested on the whole data to test if it fits and all data has been accounted for. The individual participants' health seeking narratives were accounted for in this model albeit with variations among superfast cases who lived with illness for less than a year compared to those who lived with the illness for decades.

Many women wove their health seeking narrative with the difficulties, challenges, frustrations and disappointments of living with fistula. While, to a researcher, an objective health seeking pathway should be devoid of other life events, to the women the context is inseparable from the experience. It is this rich and nuanced data that became the hallmark of my research that is presented to further illuminate these pathways. The narratives with fistula patients led us into a glimpse of their entire life story centred on the fistula illness.

Ideal superfast cases of obtaining fistula surgery at the first step of seeking treatment in hospital are rare, with only 3 out of 99 women who sought care at hospital at the first undergoing corrective surgery for either RVF or VVF. For instance, a participant had undergone her first surgery at recruitment is only represented at level 1 in the composite pathway. The proportion accessing surgery increases upon multiple visits at the second and subsequent steps at hospital visits. A close scrutiny of the pathways reveals that initially, women stay home, as time advanced, more women procured surgery. The extremely super slow cases are represented by women who had five or more visits to the hospital and got treatment having lived with fistula for many years.

The composite pathways show patients who had up to nine visits to the hospital before obtaining reparative surgery. With seven possible options of care at each step, namely traditional healer, NGO, stayed home, hospital, home remedy, prayer and private health care providers as the seventh option, and nine hospital visits patients in all study centres.

The model depicts general impression of individual women following linear pathways in seeking remedy for the condition. However, a few used mixed choices at the same period of time. Further, some participants had more than one surgery for vaginal fistula thus increasing the instances of their contact with the hospital.

In this composite pathway, at each step or action of health seeking, some participants exit the pathway. For instance, at step 1, there are 121 participants with obstetric fistula illness. 99 of them get to hospital and out these, only 3 obtain reparative surgery. At step 2, there are a total of 120 participants; 92 of them get to hospital and out of these 23 obtain corrective surgery. Over time, for instance at step 6, only 30 participants remain in the pathway. Only 4 participants had a 9 step pathway, as represented at the bottom end of the pathway.

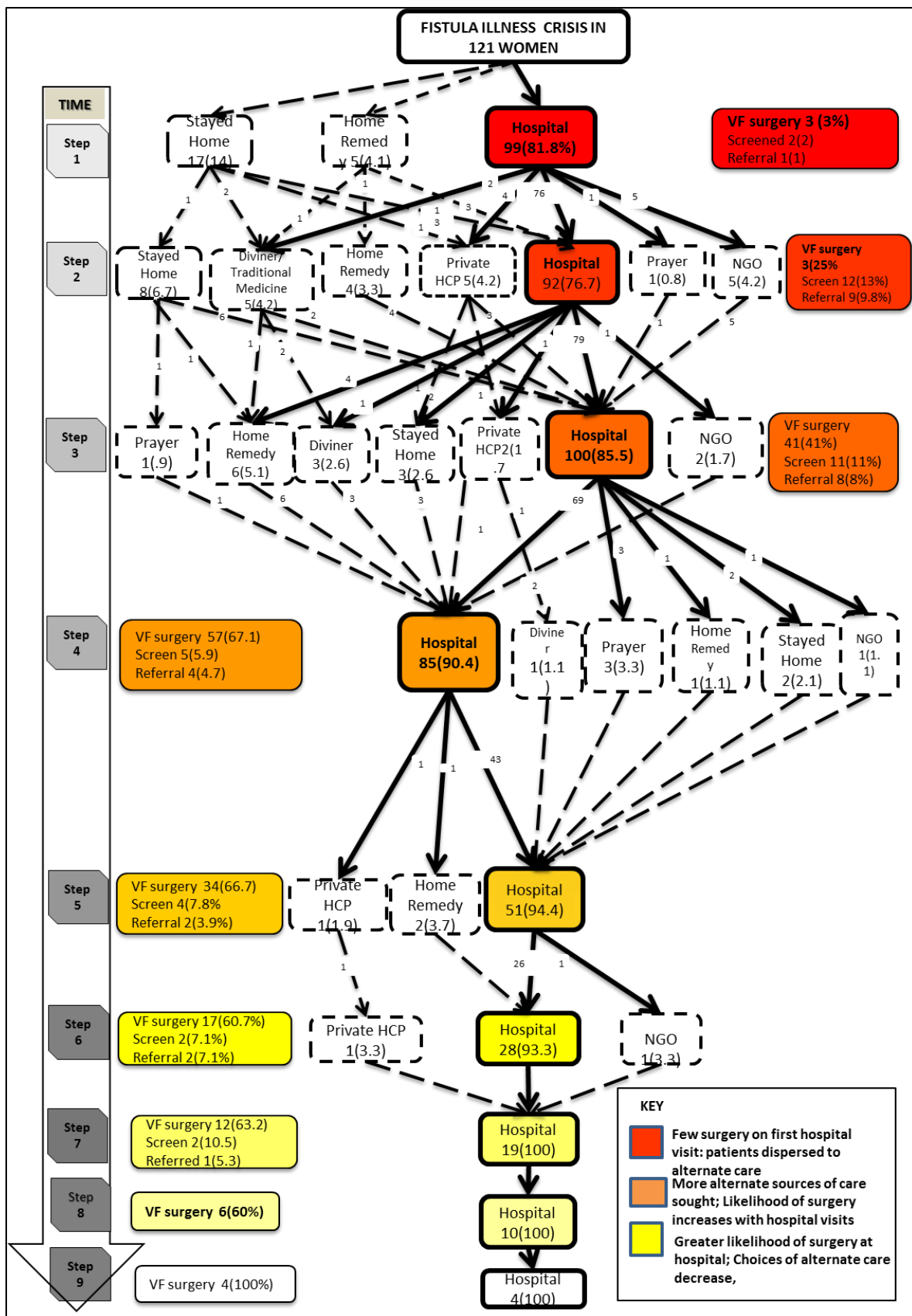


Figure 5.2: Composite pathway of health seeking behaviour of women living with fistula

But what does this pathway illustrate? What health care and health seeking behaviour issues are evident in this composite pathway? This section offers an interpretation of the pathway based on the participants' narrative of their experiences whilst seeking treatment.

The hospital as a key pathway disperser

Contact with hospital is not guarantee of treatment for obstetric fistula. Thus many participants had multiple hospital visits to different facilities over decades without treatment. Secondly, unsuccessful surgery may lead to the women staying home for long periods of time before they attempt another visit to hospital. A participant who had lived with the illness for 34 years is an example of this fact. Having obtained fistula surgery within two years of onset of illness, it was not successful. She went to different hospitals then stopped making other efforts to obtain surgery when she realized it was expensive. She then sought, in her HSB pathway, to use herbal medicine, staying home, home remedy, prayer in addition to going to the hospital. She explained:

There [hospital] they examined me and said my bladder was destroyed. They told me to go and eat well for three months and then I go there so that they can try treating me. So when I saw that the money required at Kindu Hospital was a lot, I went to Russia hospital [...] I was treated there but I did not heal at all. The urine continued coming out. They then told me to go back there but *I was afraid*. I went to another hospital in Kiambu called Nazareth hospital. I was treated there and was not healed. So since then I have stayed in the house; I don't go anywhere but tolerate the problem since that '79 until now, 2013. That's when I heard the radio advertising that there will be a doctor here who will come and help the women who continue to have urine coming out. That's when I tried and came here [KL5H] and I have been treated (030_3, 53 years, 1 child, Kisii)

It could be that patients did not sufficiently explain their symptoms and therefore given treatment and discharged, or at the time she had an infection and was given treatment before the fistula could be treated. But due to the costs involved, she never returned to hospital. The interplay of unsuccessful surgery, lack of money and alternative medicine keep women staying with fistula in the communities. Indeed women expressed frustration with multiple surgery and unsuccessful repairs. High participant expectations that

treatment meant the urine incontinence must stop also caused women to refrain from going back to hospital for further surgery.

The multiple hospital visits for treatment were a series of costly visits even though the participants could barely afford it. In this instance they gave up and learnt to tolerate their situation. A main impediment to women access to hospital is lack of money to pay for procedures related to or for the fistula surgery. For instance, a participant who lived with fistula illness for thirty years described lack of money as an impediment to treatment.

I could not get money [...] because we were told these things require money. I was operated on and they told me when I go back I go with money. Eeeh. And I was told it was a lot of money and I said where will I get all these money, even if it is ksh100, 000 where will I get it from? I am from the rural areas and there is no one who can give me. So I said *let me just stay* if it was written for me like that I will stay and die like that. Eeeh. So when my son heard about it [the camp] he told me, ‘mother, come so that you can be treated’. (033_2F, 54 years, 3 children, Siaya)

Participants reported lack of provision of proper information regarding their fistula illness from health care providers that they encountered. This is a shocking reality represented in the face of participants who go to hospital numerous times without getting proper examination, diagnosis and reparative surgery or referral to fistula repair centres. It is one of the circumstances that women meet in hospital before they take other steps to the other alternatives in the health seeking pathway other than hospital. A typical narrative that demonstrates this is the story of a participant who kept coming back to the same facility five times before she was informed that her condition could not be treated there. This then meant she had multiple contacts with one facility without definitive treatment, and ultimately she was not offered an alternative referral as to where she would get proper treatment. She went home to ‘stay with her illness’.

In Kakamega I received the operation [caesarean section]. So they told me that it was dirt. That is in the stomach and it will just be over. When I went back home the problem continued. They gave me another appointment. So when I went for that appointment, there was no doctor. And they gave me another appointment. I went and they told me, ‘you could have been operated on in the theatre but there is no water. Go back, and they gave me another appointment. I went back on that date,

and so they told me there was no cotton wool to do that job. I went back home. They gave me another appointment. So I went and they put me in the ward. I stayed in the ward for two weeks. Then they said, ‘*** when we examine you, we see that you are destroyed badly, and we cannot’, so there they said the truth. [...] ‘So now I will go back home?’ Mmm [yes]. ‘Without treatment?’ ‘Without treatment’. I went back home. I went to Mission and they told me to go back to Kakamega, ‘we don’t treat people who are like this’. I said I have gone many times to Kakamega and they shocked me and they told me this last time that they cannot; now again I am to go there? So I went back home and stayed [...] they refused me in Kakamega now am destroyed badly and it’s not possible. Now I said, when they said I was badly destroyed and it was not possible. And I have tried Mission hospital and they have taken me back there, it is like it has failed. I went home and stayed. (036_1F, 57 years, 1 child, Kakamega)

She is not alone in the narrative of health care providers missing fistula diagnosis, or failing to refer patients appropriately with enough information about their condition and where they can obtain treatment. As demonstrated in the composite pathway, most women did not receive corrective surgery at the first point of contact with the formal healthcare system. A paltry 3 women did receive VVF surgery at their first visit to hospital (step 1), and another 3 screened and referred. The remaining 93 women are not attended to appropriately in their first step at the hospital. A similar impediment faces the 76 who come back to a hospital as the second step, only they are joined by more who had opted to stay home or seek home remedies. Others however stayed home or tried prayer, alternate home remedies and traditional medicine and returned to the formal health system much later in their treatment seeking trajectory.

Another significant finding of this pathway is that women undergo multiple surgeries in their quest for healing. Some had the surgeries at different hospitals and VVF camps, some by same or different surgical teams. Thus, from the examples shown above, the multiple visits are characterised by a health system that did not have enough equipment and expertise to treat the illness, at times failing to refer the women to facilities that would. Secondly, if money was required for tests, the participant was not likely to afford the test. Third, when a participant is afraid to go back to hospital she is not likely to get treated.

The frustrations represented in the pathway to accessing treatment may have led to some women ‘just staying home’.

Basing on the findings of the health seeking behaviour pathways of participants and the contextual issues surrounding the length of time lived with and fistula illness, a conceptual framework is presented in section 5.5 below.

5.5 A conceptual framework for health seeking behaviour of fistula patients

The numerous factors presented in the women’ narratives of health seeking behaviour and the composite treatment pathways during obstetric fistula illness are summarised in a conceptual framework that depicts contextual issues surrounding fistula treatment in Kenya. Figure 5.3 illustrates the conceptual framework.

Over time since onset of fistula illness crisis to surgery, the obstetric fistula patient experiences broad contextual and intervening factors that determine each health action they will take. The intervening factors overlap to produce varied effects seen as steps in the health seeking behavior patients with obstetric fistula.

The intervening context includes economic and environmental factors such as availability or lack of information, transport, cost of surgery; social factors such as presences of supportive family especially the husband, peers, and community groups, *chama* (women’s support groups); Health system factors such as lack of missed diagnosis, no screening, no referral, surgeons, surgical facilities, individual provider response to fistula patients influence their health steps/ actions.

Ultimately, intervening contextual factors – economic, social and health system – interact with the individual stressors to determine their sequential progress and steps in the health treatment seeking pathway. Although individual patients may live in the same contextual

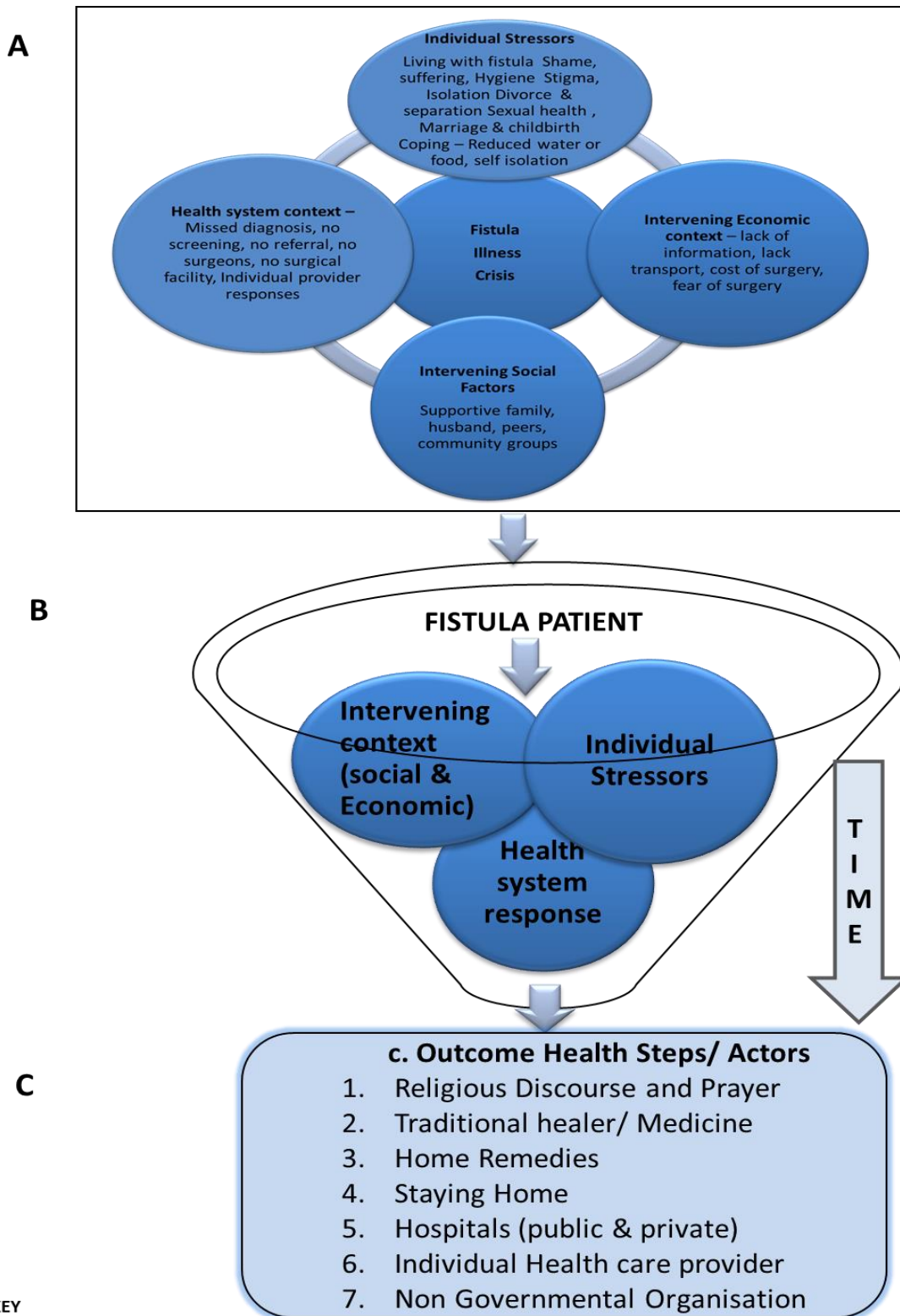


Figure 5.3: conceptual framework for health seeking behaviour of obstetric fistula patients

environment, their individual stressors uniquely impress on how they respond to and reach out for help in this crisis. First, the individual stressors include the entire experience of living with fistula illness. Implicit in this is the shame, stigma and isolation and the entire moral experience of the disease. Whether a patient discloses and seeks help for fistula illness depends on the strength and quality of their moral experience of the illness. Further, disclosures relies on the social support they then obtain to seek treatment in their quest for healing.

Secondly, hygiene challenges posed to patients hinders them from accessing public transport to seek treatment. They are caged in their own lives avoiding public scrutiny and shame. Instances where transport is provided for by an NGO to hospital, women are more confident than if they use public transport.

Third individual stressor is divorce and separation that plays out both on the social and individual stressor role. Divorced or separated women have little support from spouse in their health seeking trajectory, especially when money for transport and hospital costs. On the contrary, women who are supported by their spouse interact better with health systems. Finally, individual coping mechanisms like self-isolation if occurring in a woman who doesn't have sufficient information on the illness then she will not be able to get social support nor contact the health system and obtain surgery in time.

5.6 Summary

The onset of fistula illness and its symptoms present a major crisis to the lives of women who endure it, signifying a deviation from the 'normal'. Women respond to this crisis by instituting health seeking behaviors that range from staying with the illness to actively seeking remedy using home remedies, consulting informal channels such as healers, prayer and formal hospitals. The hospital is however a popular choice in women's narratives dominating the health seeking pathway, although women who seek fistula treatment

perceived it as not meeting their expectations and needs. The long pathway introduces a trajectory of a chronic illness to an otherwise short term and curable illness. Individual stressors and contextual factors determine the length and nature of health seeking pathway that women exhibit, presenting opportunities for intervention to improve the treatment experience of women living with fistula illness.

CHAPTER 6: REINTEGRATION

This chapter focus on the reintegration period, after surgery one year postoperatively. The aim is to document the women's experiences immersing back into a community that was previously supportive or shunning them because of their condition. The chapter is divided into three main parts. The first part addresses the enabling conditions that support the reintegration of women following corrective surgery, i) social support systems (social capital) at the family and community level ii) social interactions during reintegration iii) skill training and iv) success of surgery. The second part presents the disabling challenges that women face that are likely to slow down their return to normalcy namely i) gender role insufficiency ii) fertility concerns iii) divorce and separation iii) sexual health, abstinence & marital challenges. The third and final part of the chapter examines the conceptual framework whose core categories are incorporated in the substantive theory of regaining normalcy for patients with obstetric fistula.

6.1 What constitutes healing, reintegration and return to normalcy?

In this chapter I argue that healing and regaining normalcy process starts at the crisis of recognizing symptoms of fistula illness to when the previous normal state as before illness is realised. Thus, the women are moving along a continuum of healing. Multiple attempts using individual agency and coping skills, as well as social support (family, community) and vital linkages to care in the health system characterise the process of regaining normalcy.

As demonstrated in the chapter five, treatment pathways are mostly convoluted and complex trajectories that contribute to the chronicity of fistula illness. Having obtained surgery, I present women's narratives along the continuum of healing. Notably, living with fistula is a status that may endure after unsuccessful surgery given the persisting physical, hygiene, social and dependence issues that remain after surgery.

Attempts to return to normalcy lead to four possible outcomes. First and most ideal is when women may be fully reintegrated to life before the illness. Secondly, partial reintegration may occur when women are moving towards a life similar to that before surgery but are still held back by disablers. The enabling and disabling factors to reintegration are described. The third outcome is the status of not reintegrated, where women are still living with fistula. There is however a fourth emerging regaining normalcy outcome of fistula illness and treatment; new integration. These are women who start a new life away from the social setting before occurrence of fistula illness and surgery. Integration for them is possible in the presence of three main conditions; agency, reinvention, independence.

Reintegration of fistula patients after fistula is recommended by the world health organisation and many a fistula surgeon. The process however is less clear. For participants in this study, their surgery comes at a time when living with fistula has had dire consequences on their social interactions. Their lives have also been disrupted on the sphere of the economic and reproductive careers. The return to normalcy in these and other realms of their life before fistula illness becomes their focus after reparative surgery. The process of reintegration is modelled on enablers, disablers and reintegration needs of participants.

6.2 Enablers of regaining normalcy

6.2.1 Support by family and spouse

The family is the first source of support to woman following corrective surgery. It is the immersion point where women gain re-entry into a previous community but having undergone surgery. It therefore is the departure point in women's reintegration journey. Participants are often discharged with instructions not to undertake heavy manual work. For most women, societal expectations for them to perform house chores meant that this

would be neglected and they thus needed help for them to follow this discharge instruction. Moreover, they needed to sustain themselves financially, be encouraged psychologically and live in a clean environment. The family thus became their supporting unit, either natal or marital family and in other cases, the children to the woman.

Family support is an enabler to the fistula patients' reintegration. The family is strategically positioned to offer the first form of social interaction and acceptance to a woman with fistula. Moreover, they are likely to be the unit that provides her material needs during illness and the recuperation period. Thus, support from the family members becomes the core upon which various institutions and community can add to. In the absence of strong family support, the women may have to start a new life elsewhere, often out of the previous social setting.

Married women are in a unique position because often, normally, they belong to the families into which they have married. But with the occurrence of fistula illness, they are likely to be rejected by the marital family members. In dire cases, as demonstrated in chapter four, they may experience divorce and separation. This disintegration of their marital life is detrimental to their social reintegration after fistula surgery, since they cannot regain the normal state as before fistula illness. The absence of spousal support is perhaps the second greatest disabler to reintegration after incontinence. Women with spousal support found the greatest comfort and did not experience marital loss. The support offered to a woman recovering from fistula surgery is crucial to her recovery and regaining normalcy. Granted, it reaffirms her position as a wife and begets hopeful expectations in regaining her previous reproductive capability.

The importance of spousal support is demonstrated by their conducting household chores that would otherwise be physically strenuous and prohibited in the 6 month recovery

period, for instance fetching water and cooking. A participant from an urban area explained:

My husband would come and check if there was no water he ensures that he fetches it, cooks and then he leaves and returns something around 9:30 or 10 o'clock and when he is given a *matatu squad [work]* he goes and then comes back. (004_2, 24 years, 2 children, Kiambu)

Spousal support is also offered in terms of sexual health and adherence to discharge instructions that requires women to abstain from sexual intercourse for 6 months after reparative surgery. A participant whose husband is very supportive of her after surgery appreciated that he understood and did not bother her to relate sexually. Further, he would still walk with her and accompany her for long distances. However, this support was piling in the light of an unsuccessful surgery and residual incontinence that was bothering her. Her husband confirmed this in a separate in-depth interview:

Our relations right now is very low. Mmm the relations between me and her reduced when that condition occurred. I am even the one sometimes who tells her to come out of that state of thoughts. Even the love that we had with her in the beginning, it has reduced. Because even when I tell her that I love her she says, 'you love me, a person who is like the way I am'. So it becomes I mean it's not easy for me to tell her that I love her. Because if I tell her that she feels bad and tells me 'you are telling me that because you see that I am like this?' (KII 006_1, Spouse)

This husband had not left her during illness but stayed and supported her morally and materially during her health seeking behaviour. After several unsuccessful surgeries, her psychological wellbeing is obviously low but he is the one offering her moral support and persistence to pursue treatment. Compared to other women, she is still married, has a home to live in and is still pursuing healing. They have lost two pregnancies through miscarriage in an attempt to regain their reproductive function. The role of her spouses support cannot be overlooked.

Couple counselling prior to fistula surgery is perhaps one of the novel approaches to managing the illness amongst married couples. With an aim of obtaining better

understanding of the nature of fistula illness and its treatment, the husband is counselled and made part of the recovery discharge instructions. A participant who had their husband counselled by nurses reported great support and cooperation from him, unlike in many other cases where the participants had little support. For instance, participant 012-3 had been supported by her husband and her sister in-law who helped her do farming and by the time we interviewed her, she was healed. Her husband had been counselled by the nursing team at KL5H before her discharge from hospital. She explained how he supported her:

What made me happy is the fact that when I was being taken for the operation, I went for the operation on Wednesday and he came on Thursday and found that big sister, the one who speaks Kisii. She sat him down; and the day before I was taken for the operation he was asked will you follow all these instructions and he agreed that he will follow. Afterwards when I had gone for the operation he was told again to adhere to the instructions. When I left he was called again and asked to follow the instructions. [...] He said just let her come because she is my burden, I will stay with her. We have lived in peace. Since I was taken [for the operation] on 9th it is only after 9th that we can be together [sexual intercourse]. I am healed. He really took my burden and I cannot complain. (012_3, 28 years, 4 children, Migori)

From these three narratives, support to women by their husband was quite helpful to their wellbeing after surgery. Moral support, material and household chores were often elicited in women's narratives, besides cooperation on the abstinence discharge instructions. Further, the spouses corroborated this information, adding their views on what challenges they faced in supporting their wives after surgery. Perhaps, the greatest support men offer to their wives is acceptance. This acceptance is what keeps couples from separation, abandonment and divorce which is a disabler of reintegration. One participant whose wife had undergone fistula surgery explained to us his role in supporting her after surgery, providing food, material and moral support, and accepting her.

After leaving the hospital I think I have done a lot and I am not sure how to put it because you know when she comes, a sick person is someone who is just there. For instance when it comes to food you must ensure you provide what they need. I was there to ensure that she gets the food that she eats. Even the things that she needed to use I was the one who was trying to ensure that she gets them, eeh. [...] Following the way she is and I have only one wife whom I married when I loved her and this problem finds us when we are grown-ups who already have four

children and the one bringing this problem was the fifth one, there are no negative thoughts that I have had because she is someone that I still love just the way I loved her before. There are none because I am still close to her. Any different thoughts that might come because she has had an operation is not there at all. [...] So the way I saw mine until the stage where it reached and I cannot run away because when I leave her then it would seem like it is her sickness that has made me to run away and I can never tell, maybe tomorrow mine would be worse than hers so when I leave her, would she ever consider also coming back to me? (KII 012_3 Spouse)

The emphasis on spousal support emanates from the rarity of this phenomenon in the analysis. There were few instances where women talked explicitly about a supportive spouse in their quest for healing. Having described the deleterious effects of living with fistula on women's marriage, it therefore of value to understand how spousal support is obtained for these women during reintegration and how this could be replicated in future programs. The rare voice of the men whose wives have undergone fistula surgery is therefore a welcome respite in informing policy. For instance, the following spouse explains how he is able to cope with his wives illness, and support her after surgery. It seems most vital to him is that he accepts her since she got ill when they were already married. Then he can bear with the financial and homecare responsibilities that come with caring for her.

Yeah, we live together. Whenever I get some *Jua Kali* job when I come back from my *jua kali* I must also give her some cash in support. That is normal. Isn't it so? But there is no type of work I can give her, because me I had already married her. So her she can only look after the family and gardening. Is it not so? In case I get some casual work outside, we just keep on living on it. [...] But you see how we are; it is difficult for even her to fetch water. In fact I am about to go and fetch water that we can use here at home. Since I told her that she should not perform any kind of heavy work. Until she recovers fully, is when she can do them. Because even me when I had left the hospital, operation; it took me some few days resting and waiting to feel better. So since she left the hospital recently, I decided that she must also rest for some time before carrying out any chores at home. Those heavy works, she can leave for me to perform. (KII 033_2 Spouse)

Participants who received varied types of support from their spouse after surgery had better experiences of reintegration than those whose spouses were unsupportive. The role of men in fistula care is pivotal; first, they too suffer when their wives suffer illness.

Secondly, they offer an important support pillar and are likely to participate in the health seeking behaviour of their wives. Third and most significant to regaining normalcy is their support and participation after surgery. Male involvement here takes on a new dimension as the sexual health of their wives directly involves them. There are fewer men supportive of women after fistula surgery. But there are even fewer men involved in and counselled at the initiation of fistula care. There is therefore an untapped potential presented here.

In the absence of spousal support, elderly participants who have grown up children are cared for by their sons and daughters. After surgery, elderly participants who had children before the fistula illness depended on their son or daughter for support after VVF surgery and were likely to have a form of family support than those participants who had no children at all. For instance, participant 003_1F lived with the condition for almost 37 years and was supported by her daughter and son in providing financial sustenance, moral support and physical chores after surgery. In contrast, participant 037-1 has little family support, having estranged from her husband and has no surviving child. In their youth, women with fistula bemoan the loss of their children, infertility and miscarriages that ensues. In their old age, the very lack of children presents itself again glaringly in the little support they have, given the African setting where one's own children are a source of care in old age in addition to the extended kinship network.

6.2.2 Community support

Members of a participant's community had to step in and support them materially, morally and financially. At times this support was in addition to what the family was providing, or solely all that was solely available. For instance, 006-2 husband provided food but her neighbour washed and fetched water for her. She narrated:

There was a house for tenants and there was a woman who had rent there and had a daughter who was about 14 years. She is the one who I would call and she would go to fetch. I used to go for water from the neighbours. I used to call her and she

would bring me water about 3 cans and she would go and wash clothes for me. (006_2, 32 years, 5 children, Machakos)

Members of the church make a crucial support base for participants after surgery. In light of the significance of religious discourse in health seeking, support from church becomes a significant support base for reintegrating fistula patients during their social reintegration. Members of the church offer social setting and interactions with women, they also visit her and she participates in church activities as before fistula illness. Moreover, for participants, being able to participate gives them a sense of completeness, where they move from sitting behind in church to the front. They could be incorporated. The church also provides material support to participants as narrated by participant 030-3 her church and the son's church were supportive of her.

The people from my church came to visit me and bought me soap and sugar. And then where my son fellowships they brought me sugar, soap and a matchbox. They even brought me cooking oil and then since that day I remained that way. (030_3, 53 years, 1 child, Kisii)

Other times, the workplace and workmates constitute the community for a fistula survivor. 042-2 worked as a house help living in a servants quarter, during the recovery period, it is her colleague who cooked for her. She lived in the same compound where she worked as a cook and the regulations of her living quarters curtailed her church members from visiting home, thought they found her in hospital. Her colleagues took care of her:

She used to help me. She at times told me 'you are an old woman sit down I will cook the food and bring it for you to eat'. My salary and hers were the same and she had a child in college and another one in school. But then we used to help each other out and all together. [...] People from the church came when I was in hospital. What they had they gave me during that time. But then at the moment, you know, people visiting me here [workplace] is a problem. [...] You know if you want someone to come here you have to ask the boss. (042_2, 42 years, 2 children, Nairobi)

6.2.3 Social interactions

Social reintegration is perhaps best gauged by the range of social interactions a woman can exhibit after surgery. At the family level, interactions with acceptance are advantageous to a woman's reintegration. However, the family is only a small fraction of a woman's social

realm. She has to interact with neighbours, friends, church and business, economic environments. Participants have better social interactions after the fistula surgery. With the challenge of incontinence and bad smell having been eliminated, they interact more freely with their friends and peers. The family members seem to take on greater hope and view them positively, as one who can be of use to them and can live with them an improvement on their social interactions as before surgery. A quote that best describes the improved social interactions is derived from a 19 year old woman who was being supported by her grandfather. During the illness, she had faced rejection from both peers and family, but they now viewed differently after the surgery:

Right now my friends even like me. But the time I had that illness I didn't use to see anyone people used to say to each other that they shouldn't come here and when I sat down I didn't stand. And I had an odour. So I didn't want to pass by my friends place or I go greet them. But now I visit them, they also come and visit me we are just fine. [...] They do not talk about me. But they talk silently and say that she went and she was treated because of the illness she had and she is now fine. But then they do not tell me. Right now they have no issues. They now visit me and they even call me and wish for me to go to their homes [...] When I had that illness even my mother's brothers said that they should leave me alone and if I was going to die then let me die [...] And now when I healed that is when they began making phone calls saying that I should go and live with them. Now that I am well I am not stinking, but then they were told no. He [grandfather] is the only one who knows about my problem. (001_3, 19 years, No child, Kisii)

The range of participants' improved social interactions following successful surgery includes participation in church activities, women's groups, and visiting and being visited by friends, visiting family members. Overall, they are able to get closer to other people both in terms of reduced social distance and forming relationships. The resumption in women's social lives is over time as they have to renegotiate previously lost interactions such as church activity. A 58 year old woman who had lived with fistula for 22 years after she developed the condition delivering her fifth child explained to us how she was renegotiating previously lost social interactions:

Friends visit you. That time people didn't want to come near me; they said I smelt. But now I am well they are saying... these days' people are visiting me. I was even in the choir. I used to sing in tenor. Then I would see all people 'Mmhhm' and I

would wonder ‘what is this?’ and I then quit. They nowadays ask ‘where were you hiding’. I just narrate to them. They tell me sorry and that I am supposed to go back. I am going to start again with the choir because I am now fine. (007_3F, 58 years, 7 children, Kisii)

A comparison of the period before and after surgery offers a mark against which regaining a normal life as before the illness is managed and gauged. For instance, a participant who is continent of urine deems her life has gone back to normal as it was before fistula illness. She now participates in weddings, women groups, can travel to far distances using public transport and goes to the market without any problem. The range of social participation mentioned by this participant indicates a full spectrum of not only social interaction but also a high level of acceptance by the community. She compared her condition before surgery:

Now there is a difference. Before you would hear them saying ‘Bourne’s mother is smelling, she is smelling.’ Now wherever we are all they say is ‘those people can treat, they have really treated you. God can also see the poor. They have cured you. Are you really healed?’ Before when I was standing up like this, all these things; I never use to sit on these things. But now I can sit and my dress is dry. (*chuckles*)[...]People come to visit. Even in church nowadays I sit in front. Before, I would sit behind. Behind on the last row, behind and I would sit alone on the chair, afraid that I am going to smell. That is what was disturbing me. But now, it is all good. Even where there were men, I was afraid. “That man’s wife really smells. Why does someone’s wife smell like that?” So I would just sit alone, all alone with my lessa. (*Sighs*) God has really removed me from problems completely. We have even gone for two weddings. We travelled from here to Sindo and we came back and I did not see where I had to stop the driver (*laughing*). ‘Driver wait a minute’ (*both laughing*). There is no problem at all. I am well. I see that I am now very well. In fact I have gone back to how I used to be before this thing happened. Even when I go to the market, when I went to Rongo, I used to be very troubled but now when I leave my house, I come back without any issues [...] Where there was a gathering is what I avoided because I was afraid that I was going to smell. Even these women groups, I never used to go but now I do and we are just okay with them, we just joke as usual. (012_3, 28 years, 4 children, Migori)

It is as though, to their social contacts, the urine incontinence was the greatest barrier to interaction and surgery that regains continence is likely to re-establish social contacts again to a large extent. There was however women who still experienced partial acceptance on the social scene in spite being continent. This may be a sign that acceptance

was based on a higher echelon rank of normalcy; people still remembered to talk about participants previous shameful illness, a label. In these instances, the participants describe a level of acceptance and some social interactions that are helpful but not fulfilling. This reality is represented by participants who, after surgery, have received some support from family and not close community members. For instance, it seems as there is partial acceptance and partial social interactions that are at times unsupportive to this narrator:

Yes there is some change but not that much. It is not that much you know people are people. You know some are bad and others are good and you can get along. [...] It is not everyone who will like you and it is not everyone who will alienate you. (030_3, 53 years, 1 child, Kisii)

During community follow up, a range of interactions is easily identified. Whilst some participants freely invited their friends to meet us and had no qualms identifying community informants, other participants were reluctant to have anybody know about their illness. They concealed their condition and could not let us interview community members in their locality, a wish we respected in observing ethical conduct in human research.

During a visit to one participant who was free to interact with friends and family, she reports a good social interaction with peers, who are also family and members of her church a very good support system that has helped her reintegrated. Her interactions are based on the absence of bad odour she previously had:

I just sit, go to my farm, go to church and then just come back. Sometimes I go to the market and I can sit for long near someone without them feeling that bad smell that used to be there. That bad smell is no longer there. Now that is my happiness and I see that God's work is good because now I don't see, even when passing near someone, people raising their noses.

The absence of previous challenge posed by hygiene played a big role in women's re-establishing normal social interactions. Further, women who had concealed their fistula condition before surgery then had no comparison to after surgery period, since the social interactions were all 'normal' as before surgery. For instance, a participant 041-2 managed to conceal the RVF and doesn't wish to disclose the cause of her surgery though she

reported being healed and very happy with the treatment. She wouldn't tell people about her fistula because it is a shameful thing telling people would only make them to isolate her. For this participant, her social interactions were not disrupted much during illness and therefore no re-establishment is needed. However, these atypical cases are few in the general narrative of women who live with and are treated for vaginal fistula surgery. The average post-operative patient is renegotiating and re-establishing social interactions with their spouse, family members, peers, neighbours, women groups and even church.

6.2.4 Skill training, business capital and basic education

Many women expressed a hope that once they are healed, they would like to be trained in a form of skill that would help sustain their financial needs. This desire to be economically independent is one of the signs that the illness does impede women's economic independence. Further, learning skills obtains for them a positive outlook to the future in addition to practically offering them a source of income. Given the young age of most fistula patients and their low level of education, skill training may be one of the viable options through which multidisciplinary cooperation can be used to reintegrate women with fistula.

The Gynocare Fistula Centre runs a tailoring program for girls who have undergone fistula surgery. They are taught sewing bags and simple dresses and depending on availability of funds, are given a sewing machine to start off their business. During their training, they are housed and provided for transport and meals. The program manager explained how they were helping women move on with their lives through training:

It's a new program because what we realized is that we have a kind of system whereby we usually take some patient history after surgery what they want to be or what they want to be in future, some we have registered, we have enrolled them to the tailoring program and currently it's picking on well because the students who have been trained I can see they have produced very nice bags and we have teamed up with a program, well-wishers from California in the states where these patients produce a kind of women's handbags and we want in the future, the next few

weeks we want to see if we can ship whatever they have produced to the US and once they are sold the funds are channelled back to support the program in terms of training, you know there are women who would like to move on with life after the devastating injury.(KII Program Manager)

The follow-up included women who had benefitted from the centres raining program, or were currently enrolled in the training post-surgery. One who had no family to depend on was making a living out of her sewing and vegetable business. After discharge from hospital and training, she was given a sewing machine to take home with her but she was not welcomed back home. This business sustained her in a certain shopping centre at Sebit where we found her living alone. At 20 years, having lived with fistula for 5 years, she was newly integrating into society again, away from home and any previous social interactions were severed but she was hopeful about her future. In the second interview, she had moved to a larger town, Kapenguria.

Similarly, another participant who was undergoing training at tailoring program at the time of follow up interview explained to us the significance of this training to her future as she envisioned it:

I came and joined the class for sewing in January and they bought me my sewing machine. And then we live at pioneer. [I make] clothes only I have not gone to make the bags, those two are making the bags they came here earlier. [...] I shall go home with my sewing machine if I make the bags and then they sell those bags and then it is given to the one who gave my sewing machine. And then I go with my sewing machine and go work with it. [...] I want to progress with this school up to the one of making suits. I open my own account and if there are other people in my village I will tell them let us go like this and this and tell them this where I passed through. I tell them everything and help others because they are sick. Let us go like this and this, like at Sentinel. (023_1, 18 years, No children, West Pokot)

The training program also supported adolescent girls to go back to basic primary and secondary school education, although none were recruited in this study. However, it is a feasible approach to return girls to complete basic education after fistula surgery, as previously demonstrated by those who lived with fistula within the school setting. The centres managers

At Gynocare again we are still supporting students who have been abused and have been operated on, underage girls and we usually take them to school and am happy to note that currently that there are 3 students who have enrolled to join high schools and they are actually doing very well. Then we will have another opportunity like come next year we have secured some scholarships depending on their performance to join high schools and we are crossing our fingers hoping that their performance next year so that they can utilize that kind of scholarships. (KII Program Manager)

Notably, not all women and girls want to go back to formal education. Some feel they would best be assisted by skill training, and yet others by business capital. A participant who was of school going age was reluctant to go back to the formal education system secondary education and preferred that her sister would take her for a tailoring course once she is healed. She felt having been out of school for the last two years would make it difficult to perform well in class and preferred tailoring or hairdressing course. The decision to support and how to support adolescent girls would have to be made jointly with participants on a case by case basis but a valuable consideration in regaining normalcy to women's severely disrupted socioeconomic lives. Key informants also felt that the women could be more independent and sustain themselves financially if supported to do business as this quote illustrates:

So when I talk about help, if maybe there is something like a loan that she can start a business because when it comes to business; she is someone who was not educated much but she is someone who God gave the brains for business so if she gets a shop to run, you can be assured if you as a person living with her that it will grow. I am seeing that things like farming she cannot do. She used to do business that even now it forces her to send someone things like tomatoes and then she sells. She cannot carry heavy things. She is a hardworking woman that if she can find some cash to start a business with I think she can live a very good life because now she cannot perform heavy chores like farming. (KII 012_3 Spouse)

Thus, skill training and provision of business capital dominated women's narratives of financial independence in the reintegration period following obstetric fistula surgery. In relation to the other emerging theme of dependence for sustenance, there seems to be a positive bearing of skill training and educational opportunities on the wellbeing and reintegration of the woman who has undergone fistula surgery.

6.3 Surgery Outcomes, residual incontinence and unsuccessful surgery

Surgery outcomes have a bearing on the return to a normal life for fistula patients. Comparing participants whose most previous surgery has been successful with participants whose surgery was unsuccessful reveals that participants who have unsuccessful surgery face difficulties in reintegration. For instance, a participant's narrative, at nine months post - surgery has not healed and still has urinary incontinence. In addition, she reported to have developed symptoms of stool incontinence, RVF and was very distressed about her condition. She termed her progress as worse off than before the most previous surgery. Notably, she has had unconditional support from her spouse. Asked to describe her condition since the most previous surgery 9 months ago she bemoaned her worsening symptoms:

It was very bad. I was very sad because whoever I went with, she came from there healed. But for me, it has become worse. I eat, I diarrhoea, I eat what, I diarrhoea, and if I doze just like that it passes [stool]. I even said, rather the way I was before because how I was before, it was just urine but "wa"! Mmmh, I cannot hold. When it [stool] comes, it just passes and I cannot say that I eat this food today and tomorrow I eat differently. Mmmh, I pass diarrhoea 24 hours. I feel now there is a problem even how I was going to work earlier, right now I cannot go. How will I go? It's hard, I am just here. (006_1, 28 years, 1 child, Vihiga)

Participants whose surgery is unsuccessful may face similar challenges to those before surgery. Further, in the reintegration period, they are faced with unfulfilled expectations about the surgery they had, and little hope of recovery, as seen in the case of 006_1F who had a surgery but developed RVF afterwards; she has ill psychological health with suicidal thoughts, and even resents the very person who linked her to care. Notably, she had been promised/ scheduled for a urinary diversion surgery which she had yet to undergo. Her ill psychological frame suggests she has lost hope in the treatment process. Her social interactions are minimal. Since she has spousal marital support, the researchers expectations was she is better situated to reintegrate when compared to 003_3F, but it seems, this support is not sufficient in the absence of the most visible sign of healing, that

of urinary and faecal continence. The interview with her spouse reveals that they are anxious to get a baby and these gender roles and expectations of her could be further contributing to her depression.

It is not sufficient to conclude that successful repair guarantees reintegration and resumption of normal life. For instance, 008_1F narrative at six months shows that though she has healed after 6 years living with fistula and numerous surgeries. She has problems settling back home due to conflict with her stepfather and negative family interactions. She has to live on her own and fend for herself, and faced with a forced customary marriage has to sever contacts with her kin. At 21years, she is ill prepared to lead life on her own but has no choice, explaining;

The day I left Eldoret and went home, there in Pokot in Sok it was in December. I went home and stayed and did my work and I just saw that my father was bringing up a lot of issues. He wanted to bring up his issues the ones I told that day and I said “ah”, he said you are coming to my home and then bring a problem again, you shall bring problems when you live in this homestead again you might get pregnant and then have another problem. He quarrelled with me and I then decided to come here. I have now stayed here for a month and two weeks.... I wasn't going to his place I was living at the centre. I found “nini” my house, I found another woman living in my house and we lived together. I lived with that woman without a problem and I would go to look for money and sell my things and now my father had issues he just quarrels because it is his farm so I decided to “nini”, I decided to come and came to Sebit. (008_1, 19 years, West Pokot)

She however looks at the future with a more hopeful outlook than 006_1F who has family support in form of a husband, but is yet to heal physically. Her social interactions are wider than at 9 months narrative earlier and she now conducts a small business to sustain her. She owns a sewing machine donated by Gynocare. From her narrative, things that are helping her reintegrate are being able to sustain self financially and being continent, hence interacting freely socially; on the contrary, strained family relations with close kin deny her family support that the other women recovering from fistula illness enjoy.

It seems success at surgery is not guarantee for reintegration depending on context. A dysfunctional or absent family unit impairs social reintegration, being the first agent of socialisation. Seemingly, community reproductive health and midwifery in partnership with family members can improve such a situation where biopsychosocial domains of healing can occur.

A comparison of these two who are not reintegrated and partially reintegrated with an 'ideal' case of a fistula survivor (029_1) was done. She had successful surgery after living with vesicovaginal fistula for less than 2 months. She underwent surgery through Gynocare and a repeat surgery three months later and she was continent of urine when we visited her, a successful surgery. She was well settled back to normalcy, in her words;

When I came from there I had no problem. Mmmh, I am doing okay. I don't see if anyone is taking me badly, like it was before. Right now am staying well with my friends. We are staying well with my husband in the house. I don't see any stress. (029_1, 23 years, 1 child, Bungoma)

She reports having had support from her husband materially and in keeping the discharge instructions of abstinence. She also had a sister who helped her in doing household chores. Her narrative is short, dominated by a positive outlook at life and she is jovial throughout my visit. She has been visited by a social worker after discharge to advise her and reinforce discharge instructions. The typical 'long stay living with fistula with multiple unsuccessful surgeries' narratives contrast with her 'almost ideal immediate surgery which is successful together with strong spouse and family support in the recovery period'. Her narrative sounds like a socially reintegrated person, her case is dissimilar to other participants we interviewed in terms of a short time lived with fistula and number of surgeries to full continence. She lived with vesicovaginal fistula for 2 months and had two surgeries. By the 9 month follow up interview, she was healed; continent of urine and socially reintegrated. Unfortunately, other women living with fistula do not have such a

good story and positive outcome of their health seeking narratives as Janet. She is one among few desirable, shorter illness trajectories of fistula patients.

Another participant (23_1) who had successful VVF surgery was continent of urine had enrolled in the Gynocare tailoring and rehabilitation program at the time of 6 months post-surgery interview. She is continent and reports that the outlook of the family, friends and community had changed towards her to a less discriminatory approach. However, the women in her community believe she was bewitched and will not get children again. She however has a positive outlook to life as exuding hope that once she completed the tailoring course she would be better.

The analysis in the reintegration chapter yielded the four reintegration outcomes namely reintegrated, partially reintegrated, new integration and not reintegrated that was then applied to the rest of participants. It also yielded insight into the enablers and disablers of social reintegration and return to normalcy by fistula patients that is presented in section 6.5.

6.4 Disablers of regaining normalcy

6.4.1 Gender role insufficiency

In African setup, women are expected to beget and nurture children. This exerts societal pressure on the married woman to fulfil this role and these societal pressures on the married woman with fistula to beget children are greater than the single one. Whilst both are childless; it appears being childlessness bothers the married woman more. Besides, the unmarried are not obliged to fulfil conjugal obligations to their spouse before 6 months abstinence period is over, as was the case for 003_3 whose surgery did not heal at the first trial due to having to engage in sexual intercourse before 6 months, and the hard menial work on the farm and household. Her story is captured in the excerpt below:

When I went back my husband didn't control himself and wait for the 6 months to pass and then something different happened [sexual intercourse]. But then it was not coming out so much [urine], just a little bit and when he was on it [sexual intercourse] he couldn't know if it was coming and that is why he was asking me what I went to do at the hospital. 'Did you ask them why you are not getting pregnant?' I told him no, when they examined me they said there is a problem somewhere. And I went back to the theatre. (003_3, 30 years, No children, Kisii)

A continent (successful surgery outcome) may arouse new hope of a baby and a factor that may persuade both woman and her spouse to try for a child. In other instances, the surgery is taken as a clear indication of treatment and healing and trigger expectations of immediate return to fertility. For instance, in the excerpt above, 003_3 husband expected her to get a baby immediately after surgery. The narrative of participant 003_3 is laden with experiences of gender based violence and spousal neglect. This has proven hard for her to socially reintegrate and lead a normal married life as before the illness; she instead lives with her sister. Compared to 001_3F who has never been married and is supported by her grandparents, they both have experienced a disruption in their lives but since the unmarried one has less demanding gender roles she appears more settled and less miserable than her previously married counterpart. Both women depend on natal family members for sustenance yet their narratives are different owing to the different societal expectations and pressures they experience. The central question remains as to how spouses are involved in fistula care and counselling. There seems to be a gap in the way they perceive their role in fistula care, especially after surgery.

The expected role of women in the general Kenyan society is that of homemaker, industry (farming) and child bearer. Three main roles played by women are those of reproduction and the care of young and the sick; production of goods and services and that of social functions such as in funerals and weddings. These roles are discussed as normal recovery points in the women's reintegration tales and have a bearing on and are used by the women to gauge what they deem as having resumed normal life, thereby reintegrated. Women

often talked about support in terms of having been helped to undertake household chores as cleaning and fetching water, cooking and conducting farming work implies that is what is expected of them in society. Perhaps these are areas in which external assistance begot them a semblance of normal life and as their health improved, they could be able to conduct them. There are other gender role expectations that were more problematic as they bore a remnant of the fistula illness. Infertility and concerns to beget children is a symbol of high echelon societal expectations of women to bear children, the reproductive role. These expectations are threatened when a woman is not able to bear children after surgery, either as infertility or difficult sexual relations or in keeping with discharge instructions of delaying childbirth for two years. The number of divorced or separated women is higher amongst those without children.

In this light, women are responding to and are dictated by gender roles to gauge the extent to which their lives have regained normalcy in their lives. In this instance, gendered perspectives of fistula illness are represented in the women's narratives.

6.4.2 Fertility concerns

Women experienced challenges of infertility during reintegration. This presented as a current need, even in the light of discharge instructions of delaying the subsequent pregnancy for two years after fistula surgery. At times, the concern of fertility and return to normalcy was raised by the spouse. A husband to a woman who had a stillbirth and two spontaneous abortions during fistula illness was concerned that they had not been able to get other children. He posed this question:

The urine killed two children since that period [of illness]. It has destroyed her even for things to do with getting pregnant. She does not even see the monthly blood. That ended a long time ago, she even forgot about it. She does not see the blood [periods]. I would like to know if she will be healed or it's just over like that. And can I get a child or not? Because it has been like I bear [persevere] with her and bears it and I don't have a child and I am the only son here at home, there is no other. The way you see this homestead, from there to here up to down there, it's

only me. My father has no other child other than me. (KII 006_1 Spouse)

Notably, not all women had challenges as narrated by this participant whose spouse was okay with the long wait before trying for another pregnancy. The following quote from her narrative explains:

P: Yes you know now when I got this baby I had to go for a caesarean and then you know I couldn't have another one when I had that problem and then the problem of this one because his scar hadn't healed completely. [...] So I had to stay for 5 years.

I: Okay and then the wait do you think that it is bothersome even to your husband?

R: No he is even the one who said so and I told him I stay for about 5 years. (004_2, 24 years, 2 children, Kiambu)

Many married women were however not as lucky as she was. Another participant was afraid of going through urinary diversion, fearing it would interfere with her ability to conceive. Although her husband is aware that she has severally undergone treatment for VVF/ RVF, she did not reveal to him the residual incontinence she has since the previous surgery. She also has not shared the suggested surgery for urinary diversion and instead implied to him that she is healed. Having gone through three surgeries so far, she is worried that diversion would interfere with fertility and instead wants to try for a child first. She narrated:

They now wanted to operate me again for this side I now felt it was hard. They told me they would carry an operation over here and I would have to use here [colostomy] on going for long calls. I don't know they would first close there. [...] They told me when they removed for this side I would use this for 2 months and then they would sew there. And then they would return me to use that side.[...] It was hard for me. I thought I might get hurt a lot. I saw that if they had closed the one for urine I would have no problem with that one because I can control myself with that one. I thought that that one would wait for the time if God would be graceful to me and I deliver I would then get helped then. Because I thought if I would have that operation then it would be hard to get a child. (031_3F, 29 years, No child, Kericho)

6.4.3 Sexual health, Abstinence, separation and couple marital challenges

The women face one challenge of adhering to instructions of abstaining from intercourse six months post-surgery. Often, they are torn between their physical healing and trying to keep their marital relations. This is often aggravated by a spouse who feels they have spent

a fortune on her during the health seeking journey, and moreover, she is seen as having 'healed' since she doesn't have any signs of incontinence. As the case of 03_3 shows, she had a previous corrective surgery but did not wait to finish 6 months. In the initial interview she is not sure whether six months had elapsed. In the follow up interview, six months after the current surgery, she reveals to us that they had not fully previously adhered to 6 months abstinence instruction causing fistula to recur. Her sister also confirms this and asks us to reinforce that she should not go back to her husband yet. The participant is not certain whether to go back or not. Her normal life as a married woman is definitely affected. She is also quite unhappy and even though her sister supports her, her uncertainty whether to stay or go back to her marital home gives us a glimpse of what married women who develop fistula go through.

6.4.4 Psychological health

It seems their mental anguish continues after treatment, and surgery should only set off other continued treatment modalities of care such as counselling. Some participants have contemplated suicide, especially in the face of unsuccessful surgery. In poor mental frame, it was better if the spouse was psychologically supportive, as this quote illustrates:

We ought to empower people like this in terms of advice; Keeping her busy every time and wanting to know the state that she is in. If I did not take care of her, even this one of mine, she would not have been the way she is. But I put her at ease and tell her it's a normal occurrence. (KII 006_1 Spouse)

The advice alluded to in this spouses interview is that of counselling. During the follow up interview, this participant said she was depressed since her condition worsened after discharge to RVF, comparing herself to another fistula patient who got healed after they underwent surgery in the same period. She enquired from us about a urinary diversion surgery that she had been promised will be conducted on her. She was very disturbed by the symptoms of stool incontinence occurs, she could not even go for casual labour jobs to earn money, making her husband the only person who could bring income. In the

interview she reported having considered hanging herself with a rope (suicide). She was very sad and appeared to have no hope. The need for follow up care and counselling is suggested to cater for the poor psychological state of women after fistula surgery.

6.4.5 Dependence for sustenance

Physical illness, discharge instructions and poverty make the women dependent on care even though they are continent of urine and stool after surgery. From hospital, the family appears to play a crucial role in supporting the convalescents, albeit as if they were still ill. The discharge instructions are that women should not engage in strenuous work. However, they have gendered responsibilities such as fetching water from the river or firewood, cooking and gardening. They therefore depend on other family or community members to perform these chores on their behalf. In addition, women cannot engage in economically meaningful activities or work and financially they have to be supported by kin.

Women suffering vaginal fistula live with the condition for long, but once the patients undergo surgery doesn't mark the end of dependence. Given the discharge instructions of avoiding strenuous work and physical activity, performing previously easy chores becomes difficult. They are still expected to eat well and return for check-up at 6 weeks to expedite their recovery. This leads them to depend on their kin for sustenance, both materially and in household chores.

They attempt social reintegration but without bargaining power/ at a lower power position. Participant 003_1F aged 62 years lived with the condition for almost 37 years. She was supported by her daughter and son in providing sustenance, and other members of extended family. For physical chores, her grandson helped. Despite the numerous points of support, including her church, her narrative is that of dependence, financially and physically, since she is within 9 months of surgery and her physical health is not good, may be due to the surgery and her advanced age of 62 years. A daughter to an elderly

woman who had fistula surgery explained her mother's dependence for financial and material sustenance 9 months after surgery thus:

And then she was treated when she was living in another house that has collapsed. ... I even came recently and it was carrying bricks from there up to here and she didn't heal and carrying bricks from there up there, it was very hard for her and it even made her ill that she went to sleep ... And now in brick making I have to look for someone who will come like the one they have made out there and pay them. They step on the earth and if I have the time I just form bricks because she can't. Now those are the challenge we are experiencing because she cannot work so those are the challenges... but then she cannot pull nor carry a big jerry can to go fetch water now, it is even better she used go a long time ago but then now... she can't if she doesn't find someone to go fetch her the water she just stays in her house without water and so pulling is hard, from the well. (KII 003_1 Daughter)

Her dependence on family is similar to the previous two narratives from 003_3F and 001_3F who are cared for by natal family. From hospital, the family appears to play a crucial role in supporting the convalescents, albeit as if they were still ill. The family members to these participants shoulder the financial constraint of taking care of their kin, although in numerous ways reaffirmed willingness to support them despite these financial difficulties. The grandfather and guardian to participant 001-3 explained the dependence of women who have undergone fistula surgery on their family in this excerpt:

Other people from here can let a child like her to go and tell her to go to Nairobi and she is chased and told go and look for your father and mother. But I am merciful because they are my grandchildren. I say that I stay with them and I will share with them my poverty and when we sleep hungry we shall all sleep starved and when we eat we shall eat as one that is what I decided. (KII 001-3 Grandfather)

The concept of dependence for sustenance permeates women narratives, from the young married to the older women, whether married, separated, and even those who were never married before. Although their being supported is a welcome step in the face of healing women with fistula, it raises the significance of care for women with fistula illness to that not previously recognised. Granted, the women do not need physically care as that accorded patients in homebased care for chronic illness. But it does have serious financial and moral costs on their family, and turns them into dependants. Although key informants in numerous ways reaffirmed willingness to support them they expressed facing financial difficulties.

Certain conditions made the urban areas sampling here different and a bit more difficult. The same conditions however account for the different reintegration status. For instance, most were engaged in meaningful business or employment thus was mostly unavailable to give us an appointment. Compared to those in the rural areas, the economic status of urban patients is much better with a few even owning their own homes. Secondly, they admit to receiving help from those around them like neighbours and friends after the surgery even though they didn't know about the fistula.

But peculiar to women in the urban areas is the high level of concealment of fistula symptoms before surgery; almost all of them were able to hide the fistula and only told people after they were repaired. Moreover, a few still say they can't tell people that they had fistula even though they were now healed. Most admitted to starting work a few weeks or months after their surgery because they have no one to depend on. Amongst urban participants, all of them reported significant improvement with the incontinence symptoms except one who is was experiencing urine incontinence. It could be that this high level of concealment of fistula illness has enabled urban dwellers to participate in economic activities, lessening their need to depend on family and friends for sustenance. It is also because prior to surgery, they were engaged in small business and were not economically as deprived as their counterparts from the rural areas.

6.5 Conceptual framework of regaining normalcy for fistula patients

The healing and regaining normalcy process starts at the crisis of recognizing symptoms of fistula illness to when the previous normal state as before illness is obtained. Thus, the women are moving along a continuum of healing. Multiple attempts using individual agency and coping skills, as well as social support (family, community) and vital linkages to care in the health system characterise and impact the process of health seeking.

Treatment pathways are mostly convoluted trajectories of time, place and person the assistance is obtained from. This complexity contributes to the chronicity of fistula illness.

Attempts to return to normalcy lead to four possible outcomes. First and most ideal is when women may be fully reintegrated to life before the illness. Secondly, partial reintegration may occur when women are moving towards a life similar to that before surgery but are still held back by disablers. The third and most undesired is the status of not reintegrated, where women are still living with fistula. There is however a fourth emerging outcome of fistula illness and treatment. This is the women who a start a new life away from the social setting before occurrence of fistula illness and surgery; a new integration. Depending on their agency, reinvention and independence integration for them is possible. Living with fistula is status that may endure after unsuccessful surgery given the persisting physical, hygiene, social and dependence issues that remain after surgery.

6.5.1 Reintegration Process

Basing on the study findings, the characteristics exhibited by a participant after surgery are largely influenced by their experience of the intersecting enablers and disablers of the reintegration process. The complete list of enabling and disabling factors to regaining normalcy for women with obstetric fistula are presented in table 6.1.

Table 6.1: Enablers and disablers of reintegration process

Enablers	Disablers
Is continent / successful surgery outcome	Incontinence/ unsuccessful surgery
Can perform her gender roles as expected by society (fulfilled gender roles)	Gender role insufficiency
Continuity in disrupted life goals and Regaining reproductive capability	Infertility
Economic independence (Has no economic dependence for sustenance) Skill training & education	Dependence for sustenance
Marital Stability	Divorce and separation
Socially supported & accepted (social capital) Positive social interactions	Negative family and social interactions
Good psychological health	Ill psychological health

6.5.2 Continuum of Reintegration Outcomes

To answer the question of who is a reintegrated fistula survivor, the women seem to be situated on a continuum of two extremes; the ideal reintegrated on one end and not reintegrated on the other end. Some women appear to be partially reintegrated, with the enablers moving women towards the desirable reintegrated end and disablers pushing them towards the undesirable outcome termed not integrated. However, in regaining normalcy, other women moved away from previous social settings to start a completely new life for themselves. This group was newly integrating. This categorisation was applied to all participants' narratives obtained during community follow-up. The interplay between enablers and disablers of reintegration is depicted in Figure 6.1.

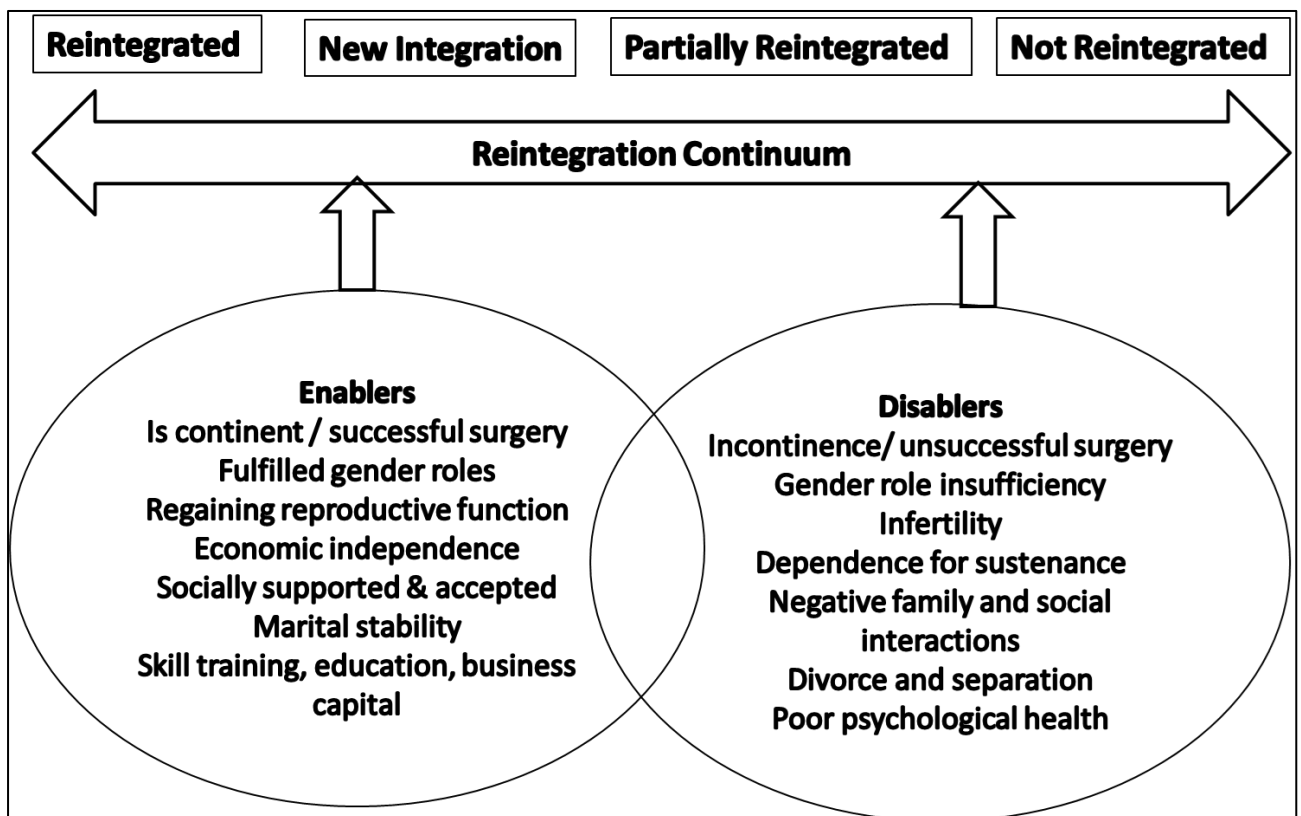


Figure 6.1: Continuum of reintegration outcomes for fistula patients

A program that emphasizes enablers and eliminates disablers is most desirable for managing obstetric fistula patients' reintegration. Such a program should also seek to

eliminate obstacles in the health seeking behaviour pathways. It would be guided by a framework that would help assess needs for and provide biomedical and socioeconomic support to fistula survivors. The framework shows interactions between enablers and disablers to reintegration.

6.5.3 Conceptual framework of Regaining Normalcy

Basing on the data regarding women's experience with obstetric fistula, the process of regaining normalcy for fistula patients is presented in Figure 6.2. This conceptual framework of regaining normalcy combines three basic conceptual frameworks generated from data in chapter five and six. First, it includes Figure 5.3 which shows the interplay of concepts in the illness crisis, health seeking behaviour and treatment pathways of fistula patients numbered as A. Secondly, it introduces the possible intersection between enablers and disablers of reintegration, resulting in four normalcy outcomes as outlined in the conceptual model Figure 6.1.

The conceptual framework in figure 6.2 therefore depicts three overlapping phases of a patient with obstetric fistula after childbirth. First, living with the fistula illness encompasses illness recognition at the onset of crisis and response of the participant to this crisis manifested as health seeking behaviour. Secondly, obstetric fistula surgery marks the turning point in women's attempt to be normal again, as they are discharged into their communities where individual and contextual factors enable or disable the process of regaining normal lives. The third and final phase marks physical, social, psychological and economic recovery to obtain their previous health as before the illness leads to four possible outcomes.

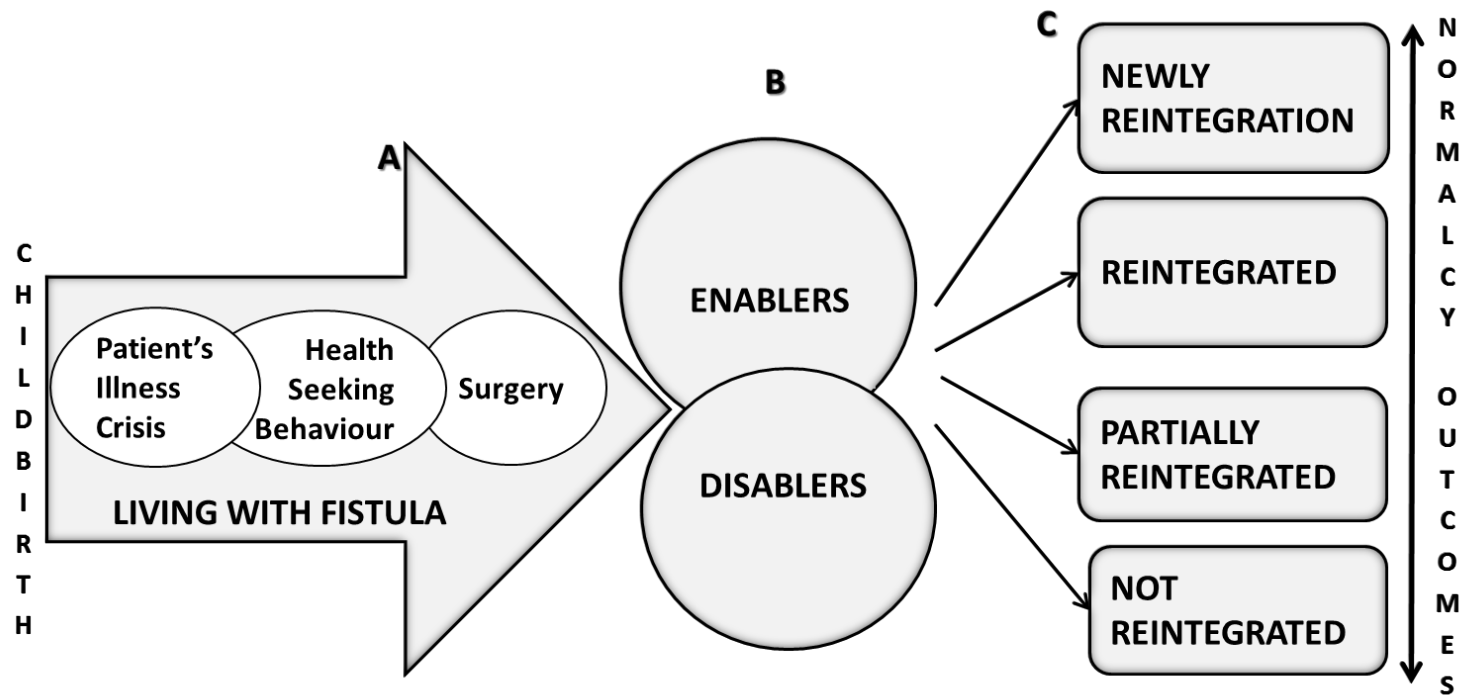
The conceptual framework sums up the participants experience of these three phases of her illness career, a) living with obstetric fistula and the ensuing health seeking behaviour and b) obtainment of surgery and the concept of enablers and disablers of regaining normalcy

and c) the reintegration outcomes of new integration, reintegrated, partially reintegrated and not reintegrated. Thus, the framework sums up the work discussed in detail in chapters four, five and six showing interconnection of the various concepts.

I argue that obstetric fistula is a chronic illness that introduces crisis, moral suffering & physical, psychological and socioeconomic disruption to women's lives in varied forms. Living with fistula and the ensuing treatment seeking pathways and the characteristic health behaviour depicted by patients with fistula is therefore part of a larger continuum of women's attempts to regaining normal lives. In their quest for healing, patients with fistula meet a health system that is unresponsive to their needs. It is for this reason amongst other personal preference and habit that women seek alternative modes of therapy, most of which are dysfunctional. The pathway may take a few months to years, introducing the chronic nature to an illness that is otherwise curable. After surgery, the process of reintegration results in four possible outcomes of regaining normalcy. These outcomes are dependent on the interaction between enablers and disablers of the reintegration process that overlap in an individual woman's life.

I present my final argument that, basing on this framework, a comprehensive obstetric fistula treatment project can carry out interventions at different levels. For instance, using narratives of childbirth, key history can be used as an opportunity to identify women who could potentially develop obstetric fistula perinatal period, and institute appropriate screening and diagnostic measures. Upon diagnosis, the ensuing crisis of obstetric fistula illness can then be promptly managed through physical, psychological and social interventions.

Khisa's conceptual framework of regaining normalcy for fistula patients



Key:

- A** – Living with fistula constitutes patients struggle with illness crisis, which they respond to by health seeking behaviour patterns and pathways and obtain surgery
- B** – After surgery, enablers of reintegration interact with disablers of reintegration after surgery
- C** – Patients lie on a continuum of four possible outcomes of regaining normal life for postoperatively

Figure 6.2: Khisa's conceptual framework of regaining normalcy for fistula patients

The treatment seeking pathways would at this level of intervention be shortened if appropriate care is offered to patients, focusing on increasing access to fistula surgery by experts at little or no cost while eliminating other dysfunctional pathways such as home remedy, traditional medicine and healers.

The third level of intervention would occur after surgery where the factors that enable a smooth regaining of normal life such as regaining bowel continence, having social support from peers and family and economic and skill empowerment are utilised. At the same instance, presence of factors that disable regaining normalcy such as divorce and lack of family and social support, poverty and lack of sustenance and are mitigated and eliminated. The aim here is to have as many women reintegrate, or newly integrate, but fewer or none who are partially reintegrated or not reintegrated. One cannot however make an assumption that after surgery women will automatically reintegrate without further psychosocial and livelihoods support. Inherent at this stage of the framework is the need for multidisciplinary teams that may be integrated with the core work of biomedical experts in fistula treatment.

Although the scope of this research work was to culminate in generation of substantive theory and conceptual framework that fits the data; the work presented herein offers opportunity for further testing of the framework in intervention research and possible pilot implementation to treat fistula patients in Kenya. In this framework are inherent opportunities for improving care of fistula patients.

6.6 Summary

A comprehensive framework for treating fistula patients should focus on prompt diagnosis and improving health seeking behaviour of patients, shortening the length of time and number of points of contact that patients with fistula deal with before obtaining treatment. In addition, after fistula surgery, one cannot assume that the woman will automatically

regain their normal lives as before fistula illness. Interventions must be put in place to obtain better outcomes at regaining normal lives and eliminating negative outcomes of partial reintegration or failure to reintegrate. The framework thus can be used to better understand the points of care that should be instituted to diagnose, treat and reintegrate fistula patients, thus offering holistic care to fistula patients. The findings presented in this chapter and components of the framework are further expounded on in the discussion chapter of this thesis.

CHAPTER 7: DISCUSSION

This chapter presents a discussion on how living with fistula, health behaviour and reintegration are part of a larger continuum of women's attempts to regaining normalcy. Using qualitative research, the crisis that fistula illness poses and the subsequent coping strategies women apply in light of existing research on living with stigmatised and chronic illness is presented. In doing so, the basic tenets of the emergent substantive grounded theory of regaining normalcy for fistula patients are expounded on.

In the second part, particular attention is paid to the treatment process and outcomes of regaining normalcy, namely women who are i) reintegrated ii) partially reintegrated iii) newly reintegrated, or iv) still living with fistula after surgery. The focus of these outcomes is on the whole individual and not only physical health and urinary continence, expanding the realm of holistic nursing care. The interplay of enablers and disablers of reintegration are presented as possible issues to be addressed in the treatment programs tailored for fistula patients.

In the third and final part, a discussion of the implications of the findings on practise, policy and research is presented, making recommendations in each area. The study limitations are highlighted as well as a conclusion on some of the key issues that are presented in this work that are important in fistula care and research.

7.1 Living with fistula

The study findings demonstrate that obstetric fistula is an illness that attracts social stigma and isolation. In this study, women's accounts of suffering and the social consequences of bearing fistula dominate. Further, women's narratives present long periods of time living with an illness which they haven't obtained treatment for. Gradually, their mind set takes on a dimension of living with a chronic illness that is highly stigmatised. In addition, women have to cope with the social and hygiene challenges posed by urine and faecal

incontinence and later, find difficulty in having sexual intercourse and conceiving in addition to mourning the still born baby. There is immense suffering by women living with obstetric fistula.

The study findings are supported by other studies that have focused on living with obstetric fistula illness. The common thread amongst these studies is the reported physical, psychological, social and economic suffering that women living with fistula endure (Yeakey et al., 2009, Watt et al., 2014, Warren et al., 2009, Kabayambi et al., 2014). However, many studies have presented the experience of living with fistula, but without specific focus on the dimension of the time lived with the illness and their health seeking behaviour as presented in this study results.

For instance, Yeakey and colleagues conducted a phenomenology study amongst 45 women in Malawi on their lived experiences of fistula illness (Yeakey et al., 2009). The authors' reported that women were likely to experience strife in marriage resulting to divorce and separation during fistula illness, although other women could still get married to another husband during fistula illness. Due to societal expectations of women to bear children, fistula survivors who had children were more likely to stay on with the husband even though he took up a new wife. Women's failure to fulfil gender roles leads to feeling sadness, hopelessness, powerlessness, desperation, depression and suicidal thoughts (Yeakey et al., 2009).

Perhaps the greatest strength of Yeakey's study, in addition to rich qualitative data, lies in use of the social construct of gender in analysing data. This is useful in understanding the plight of fistula patients whilst taking into account how the macro-sphere and social context influences how they experience the challenges of living with fistula. Similarly, many women in this study either experienced marital strife and separation, inability to conceive and/ or miscarriages and difficult sexual relations. In many Kenyan communities,

women are expected to stay married and bear children. This may explain the disappointment which women expressed having separated or been divorced as a result of fistula illness, and problems in attempting to engage in sexual relations with the husband and their inability to get other children after developing fistula illness. Although Yeakey's study did not focus on reintegration of women with fistula since the study participants had not obtained successful surgery, the results point to what aspects of their normal lives had been lost by fistula illness and can be used to anticipate the participants' expectations once they obtained treatment. A jeopardised sexual and reproductive function is at the core of a fistula patients suffering. Further, the attempts of women to live normal sexual and married lives and begetting children is a possible indicator to what women desire in being normal again as expected of them in socially assigned gender roles.

This study reported women have poor coping with social stigma, isolation, and in addition, mourning the loss of a child, jeopardised marriage and possible separation as a result of living with obstetric fistula. Similarly, in a meta-analysis of consequences of obstetric fistula in developing countries, Ahmed and Holtz (2007) list social, mental, and psychological challenges of living with fistula. Focusing on two outcomes of marriage and perinatal child loss, the authors report high foetal and perinatal death rates associated with obstetric fistula and the occurrence of fistula illness results in lower women's social status and lead to divorce. First, the aforementioned authors support this study's key finding of living with fistula being fraught with having to cope with challenges of loss of the baby, and their social role as women – being wives and mothers- being jeopardised. Secondly, they report mental health illness symptoms of depression, low self-esteem, stress and anxiety. The psychological symptoms Ahmed and colleagues described were a common finding from my study. Third and divergent from the first two similarities, Ahmed and Holtz review reported infertility and poor sexual health but their meta-analysis does not

further analyse these two outcomes. This study goes further to demonstrate that poor sexual health and having to cope with challenges posed by incontinence of urine and faeces during sexual intercourse were often spoken about by the participants. Pain during intercourse and having to use separate beddings are some of the challenges cited by my study participants as having made sexual relations with their husband too difficult or impossible. The women's spouses supported this view.

Ahmed and Holtz (2007) in their extensive review of existing literature on fistula presents strong evidence collated from different primary studies from quantitative and qualitative approaches. The authors noted that the few studies existed on the topic of rehabilitation and suggested a broad social and lifecycle approach based on only one study. In section 7.3, in furthering these authors work, a midlevel theory on reintegration of fistula patients grounded in the data is presented. In addition, these authors present a suggestion, based on their meta-analysis, the need to treat women with fistula both on the basis of humanitarian and social justice and addressing their reproductive rights (Ahmed and Holtz, 2007). The issue of human rights are expounded upon in the health system response section 7.2 of this thesis.

However, it is crucial to highlight how participants in this study coped with two main aspects of fistula illness emergent in the narratives. First, how do women with fistula cope with the stigma associated with the illness? Secondly, how do women with fistula cope with the interruption caused by the chronic illness? I contend that how fistula patients cope with fistula illness mimics that of coping with other chronic and stigmatised illnesses, and that this coping, albeit mostly dysfunctional, explains and informs the health seeking behaviour patterns of women with fistula. Improving the health seeking behaviour of fistula patients thus relies first on understanding how each individual coping mechanisms while living with fistula is likely to affect their health behaviour and prompt treatment.

7.1.1 Coping with stigmatised illness

The findings of this study reveal that fistula is a stigmatised illness, and a chronic reproductive health condition. In presenting the argument, I compare the findings to two scholars who have conducted classic work on the topic of stigma (Goffman, 1963) and chronic illness as biographical disruption (Bury, 1982).

Goffman (1963) in his book, *Stigma: the management of spoilt identity* explains the original meaning of the word stigma as:

“bodily signs designed to expose something unusual and bad about the moral status of the signifier... a blemished person, ritually polluted, to be avoided, especially in public places”. (Goffman, 1963): 1)

Society categorise the attributes of normal people that are taken as ordinary and natural, a ‘social identity’. Deviation from this normal makes a person to be discounted in the eyes of society, and possession of these deviating attributes is a stigma (Goffman, 1963). An individual who then deviates from the normal attributes that are expected is a *stigmatised* person, while those individuals who don’t deviate are the ‘*normal*’

Goffman’s text is quite relevant to understanding the experience of living with fistula. Here, patients with obstetric fistula would be said to possess a stigma that is ‘an abomination of the body’, a physical deformity in urinary and faecal incontinence that deviates from the social hygienic norm of bowel control, deviating from a normal woman who is clean and continent to one who constantly smells of urine and faeces.

Shame is an attribute that arises when an individual perception of their attributes as something defiling (Goffman, 1963). Shame is a core category in women’s narratives especially around disclosure of their illness and concealment. At the core of their action to disclose or to conceal fistula illness is the feeling of shame of not being able to control urine, and of an illness in the private parts of a woman.

Previous acceptance of a normal person is lost when they present with their discrediting characteristics in public, and failure to obtain acceptance prompts the individual to correct the basis of their failure, to obtain acceptance (Goffman, 1963). The nature of health seeking behaviour of fistula patients has two fold realms; emphatic efforts that mimics the description by Goffman of attempting correction, and the other extremity, that of staying home with the illness. Even after fistula surgery, women remain in a convalescent state of one who recently had a blemish corrected. They venture out to social circles reluctantly.

Faced with lost control of bowels and hygiene challenges that arise, women first may arrange to avoid all manners of interacting with the normal people by not going to church, women groups or visiting relatives; a self-imposed isolation. The self- isolation then deprives women of vital social interactions that were previously a key marker of their identity as women, mothers and wives. But obstetric fistula patients still interact with their husband and close family members even though they succeed in avoiding public encounters. However, even in the family, there are tensions of how their husband perceives and reacts to the woman's disability, and this tension often resolves in the more common tendency of husbands divorcing and separating from their wives, or supporting them. The main issue here is that of acceptance. A husband may be overwhelmed by the fistula and walk away, others physically remain but are emotionally detached, and yet others remain and totally are morally and materially committed to support their ailing wife.

In addition to the husband, there are other family members and members of the extended kinship network who encounter, interact with and offer acceptance or rejection to a woman living with fistula illness. These acceptances and rejections bear a permanent mark on what women attribute to suffering. The tendency of participants to talk about how they thought about their illness and the reaction from family signals that the woman not only

has to deal with lost control and altered identities, they often have to manage the unpleasantness of their social interaction experiences.

In the broader social community, women face the dichotomy of acceptance and rejection or an overlap of the two. Their peers may be supportive and invite them to events but try to manage the hygiene challenges. Others simply give up and exclude the woman from events that require distant travelling events or other social gatherings. In addition, the woman questions her ability to manage her hygiene and declines to honour few invitations accorded to her by friends. The common psychological symptoms depression and feelings of low self - worth among women are in part a result of isolation.

Fistula patients interact selectively. Before treatment, they keep to situations that give rise to less rejection, and after surgery, they are careful to disclose to a select few on what surgical procedure they underwent. Although many people would be knowledgeable to their illness it was never a formalised disclosure and this 'closed knowing circles' are kept. Whilst it is a defence mechanism for the fistula patient not to disclose widely for fear of rejection, it is the very secretive nature of the situation that may not beget her appropriate community support in recovery period, and the isolation may linger unless she initiates the interactions.

Goffman describes those who are aware of and empathise with the discredited person as the 'wise', those whom the discredited person can be themselves without shame or need to exert self-control. The wise may be people who work with the discredited people, for instance, healthcare workers in the instance of women with fistula. In keeping a reflexive approach to this grounded theory research, I often marvelled at how women were willing to accept to share their experiences and offered our research team such high acceptance. We always introduced ourselves as student nurse researchers. Here, my profession as a student nurse researcher, perhaps, made patients regard me as a 'sympathetic normal, a

wise person' hence allowing us into a world they privately endured before. This presents healthcare providers with an opportunity to get the gist of suffering from the patients. They are best positioned to accept the patients for who they are, and this is because the patients consider us 'wise' on their illness. Likewise, the tendency of patients, having disclosed to a close family member about their illness, presented at hospital and confided this 'shameful' condition to healthcare providers is telling. Women may readily disclose what they consider shameful to healthcare providers at will, a level of trust that could be built on in recognising and appropriately treating obstetric fistula.

According to Goffman (1963) other 'wise' people may be those who are related to the stigmatised person socially, for instance a husband whose wife suffers obstetric fistula. The man is labelled and suffers this blemished mark as one 'whose wife smells of urine'. Similarly, the blemished mark may be to a 'son or daughter whose mother smells of urine' and is ridiculed. In this study, the participants' family members disclosed having experienced a level of common suffering with the patient, either morally through shame and labelling, or further financially deterioration in needing to materially support the fistula patient. Here the family is at the margin of the woman's experience of suffering, 'knowing' and may, depending on strength of their relationship, support her or sever links completely.

Whether fistula patients' family stay to support her in illness depends on how well the family member can cope with suffering and the amount of suffering defines their experience. For instance, the divorce of fistula patients is a pointer that marital relations may be severed in the face of illness, but other blood relations such as natal and siblings endure the course of fistula illness. Only in one instance did we find a fistula survivor having been severed from her natal family since she was an adopted child whose mother died, as opposed to marital severance which was common. This could be because in most

communities in Kenya and other African kinship networks, the natal family is the strongest supporter of women during illness and offer support even during labour and delivery. The fistula patient whose marriage ends is therefore inclined to go to her natal home, and after surgery, the married one still goes for care at her natal home until she is back on her feet.

The new integration category of women who have obtained treatment for fistula illness is fascinating in many ways. Having suffered a stigmatised condition for years, the women finally obtain treatment and are cured of some or all of the disturbing symptoms. Particularly, hygiene issues having been resolved through regained continence, one would expect these women to be accepted back into their previous social role as wives, mothers, daughters and friends. But this group tends to move away from previous social setting, for instance from her natal home, or her marital home to a new social setting, more often an urban centre. This mobility of fistula patients has been reported by Maulet et al. (2013) in the sense of therapeutic itineraries of fistula patients. Maulet et al. (2013) observed that those waiting further surgery tended to wait in nearby towns for easier access to a hospital or for economic opportunities. But in my study, the women who were newly integrating were continent and were not necessarily awaiting further surgery. This leads to my argument that these women a desire for a new start at life away from their previous known life. This desire may explain the agency and mobility of women who start new live indifferent social settings where there are no unpleasant comparisons of before and after. In the new position, few people around this woman know of her previous fistula illness and do not need to accept her, she is already normal as everybody else. New integrating women settle in urban areas where most people mind their own business without her running the risk of them investigating her past illness. Urban centres are not as closely knit social settings as in the rural area. Here, a woman is not required to reveal much about her previous illness than if she was in a rural inquisitive setup. People in the urban area tend to

mind their own business. This fact perhaps lends credence to women in urban areas who concealed their illness even before surgery. Third, the category of women who are newly integrating is possible among those who remain unmarried, either because they had been separated from the husband or were not married by the time fistula occurred. Most urban dwelling participants reported that during fistula illness, their neighbours seldom knew of their illness and its symptoms. The few who did

However, divorce and separation, and not previously married was not the only contextual factor contributing to new integration. For instance, women married other men during fistula illness. The summative context of new integration then had to be in four conditions; being single (separated or never married), being rejected from previous family setting, being able to support oneself financially and materially, and having a strong will to do so.

Similarly, (Goffman, 1963) notes of the situation of people with stigmatised illness;

“It should be added that when an individual acquires a new stigmatized self, late in life the uneasiness he feels about new associates may slowly give way to uneasiness felt concerning old ones. Post-stigma acquaintances may see him simply as a faulted person; pre-stigma acquaintances, being attached to a conception of what he once was, may be unable to treat him either with formal tact or with familiar full acceptance.” (Goffman, 1963):35

Drawing on Goffman’s description of old and new associations, I argue that it is the safety and less awkward experience of dealing with new social contacts that attracts women to start anew, away from home after fistula surgery. This also accords the woman with previous fistula illness, or one living with fistula that is not immediately detectable to ‘pass for normal’ in the new social setting.

Passing is a concept that was first described by (Goffman, 1963) as a form of information control in which people with discreditable attributes decide to tell or not to tell others

about their condition, and selectively choose whom to tell and how much to disclose. There were women, notoriously among those with rectovaginal fistula, whom not even the husband was knowledgeable about the illness. In managing the possible spoilt identity that would have risen if they disclosed their condition, concealment helps these women to pass for normal. This is possible for the illness that is not as visible as that of urine incontinence that often presents with a continuous flow and smell of urine, as opposed to faecal incontinence that may be managed by regular bowel emptying. Here bad odour and smell is what makes fistula illness visible, same as one who has a physical disability.

A fistula patient who is able to conceal the bad odour and smell can therefore easily 'pass' for 'normal'. Passing helps women avoid social isolation and stigma, shame and other consequences of living with fistula, and allows them normal social interactions. But passing and concealment may be counterproductive. A woman who is keen on , for instance, concealing rectovaginal fistula has to be careful about whom she seeks information about its possible treatment. This may hinder her obtaining correct information and delay treatment. Also, she may not get the psychological support and moral benefits that come with sharing about the problem with a friend or relative.

Concealment of fistula illness is however only possible in few cases. The point at which departure from concealment and passing occurs, as was often narrated, the relatives present during a fistula patients visit to the hospital may be told of her condition by the medical team. In this case, it is not possible for her to pass as 'normal' amongst close family who are now 'wise' about her condition. The third deviation from concealment and identity management occurs in the case where urine incontinence and the smell of urine and other symptoms reveal the participants condition without offering her the possibility of managing disclosure. The patient has little control about who knows of her illness. In this

case, the luxury of information control that patients of other stigmatised chronic illness that would present without obvious symptoms, say, of HIV or tuberculosis, is lost.

The last instances of the illness self - disclosing nature makes the management of spoilt identity difficult for the woman. She loses control over who knows of her illness, and has to manage the reactions of those who are 'wise' about her illness that may often be unpleasant. Most fistula patients fall in this category.

7.1.2 Coping with biographical disruption

Chronic illness has been presented as a bad biographical record on one's identity especially if it is a stigmatising illness (Goffman, 1963). Further, to enrich this discussion, I compare the study findings with Bury (1982) who presented chronic illness as a particular type of disruptive life event in one's biography.

Particularly, Bury (1982) presents the personal biography as a source of variation in an individual's experience of illness. In his classic paper, chronic illness as a biographical disruption, (Bury, 1982) posits:

“Illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Chronic illness involves recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others. In addition, it brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support. The growing dependency involved in chronic illness is a major issue here.” (Bury, 1982):169

The occurrence of fistula illness disrupts women's lives on many fronts. First, they lose control of normal body function, introducing with this loss a taxing demand on their ability

to observe body hygiene. Secondly, they have to mourn the trauma of losing a baby through stillbirth or neonatal sepsis. Third, their sexual health is jeopardised. Fourth, on the social front, the woman with fistula loses their dignity and face amongst their peers, and may be divorced or separated. The fifth disruption occurs on the socioeconomic front, where they are no longer able to pursue basic education if young, or participate in economic activities involving other people if they are older women. It is these five forms of disruption that last a few months for the lucky few, or a lifetime for those whom fistula illness assumes a chronic nature.

Fistula illness dents the biography of the normal self for the woman. The woman who previously suffered from obstetric fistula may after surgery attempts to regain normalcy. However, the record remains, of someone who has had a previous deformity corrected. More so as fistula touches on the reproductive capability of women, so does the significance of this biographical disruption manifest through infertility being one of the main concerns of women with fistula post-surgery. Women are eager to re-establish their reproductive careers, and those who have lost it by due to advanced age or had hysterectomy during the index labour bemoan this lost ability to reproduce. But the finding of participants' desire for more children was not universal, introducing an individual variation in the way their envisioned reproductive careers have been altered. Specifically, women who have other children were less anxious to conceive again and did not bring up the issues. On the other hand, younger women with one or no child whatsoever brought issues of fertility and regaining reproductive function more often. The aspirations of women varied depending on context.

After surgery, attempts for women to regain a normal life as before fistula illness are counteracted by this disruption. The biographical disruption has to be transcended and overcome. Practically, women whose lives have been disrupted less by the illness, often of

a short period regain normalcy easily and are likely to be categorised as reintegrated. Contrary to this, the reality of women whose lives are disrupted by fistula for decades, are divorced and without any surviving child find it hard to regain normal lives. They are likely to stay as though still living with fistula illness, or start all over as newly integrating.

7.2 Health seeking behaviour and health system (un)response

The typical health seeking behaviour of a fistula patient in this study is characterised by a sequential health steps taken to seek treatment, with multiple sources of care in the formal, informal healthcare system and episodes of staying home with the illness with or without home remedy. Those who obtain treatment in the formal sector at times undergo more than one corrective surgery, and have to pay many hospital visits. Others yet experience misdiagnosis and lack of proper information concerning their illness and referral.

Time lived with illness and Treatment seeking

The World Health Organisation defines chronic illness as ‘illness which lasts more than 3 months and is incurable’. Notably, the mean time lived with fistula illness was 8.7 years (range 1-43). Further, only 3.4% of women reported having obtained surgery in the ideal immediate period (less than three months) and a further 13.5% within a year (n=26). The chronic nature of illness is demonstrated by the majority of participants, 31.4% of who lived with fistula illness for 1 to 5 years and 43.2% for 6 to 43 years respectively.

There is scarce research concerning the health seeking behaviour patterns of women with obstetric fistula. By the time of this study, no study existed that wholly examined the health behaviour patterns of fistula patients beyond reporting the time spent before surgery. However, existing research has illuminated some of the components of health seeking behaviour similar to the study findings.

The chronicity of fistula illness is suggested though, conventionally, obstetric fistula is not classified as a chronic illness. This is demonstrated in the length of time lived with fistula illness and the length of treatment process. I contend that the chronicity of fistula illness is beyond the time spent during care process. The total time lived with fistula illness is the clearest indicator in the biography of women who suffer this condition of its chronic nature. Secondly, depending on the surgery outcome irreparable fistula present the woman with the possibility of living with fistula illness for life. Those who encounter other forms of corrective surgery like urinary diversion permanently live with the aftermath of fistula illness. Infertility is another fistula illness symptom that lingers after surgery, along with traumatic moral experiences. Obstetric fistula illness is thus in this sense, a chronic illness.

Regarding time lived with fistula illness, a recent study in a hospital in western Kenya indicated that 35% of the women had experienced incontinence for one to five years and a further 19% for over five years (McFadden et al., 2011). Similarly Yeakey et al. (2009) reports a period of 20 years living with the condition in a qualitative study of the lived experiences of women with obstetric fistula in Malawi. These authors suggest a long term nature of suffering fistula illness. My study participants unravel similar and even direr findings of women who had lived with fistula illness for up to 43 years. Thus, the chronicity of fistula illness is suggested although conventionally, obstetric fistula is not classified as a chronic illness. First in the longevity of the illness and secondly in the way the woman's life is disrupted and the normal as she knew is halted.

Other studies report similar findings to this study. Concerning the course of illness, a recent study by Maulet et al. (2015) reported that obstetric fistula illness may be viewed as a chronic illness owing to the length of care process, limitations of surgery and the persistent physical and moral suffering (Maulet et al., 2015). Reporting a qualitative study spanning 18 months in Mali and Niger, the authors stress the need for long term care, and

tertiary prevention measures, but acknowledge that the holistic approach to care, prevention-treatment-reintegration axis may be feasible within standalone fistula repair centres and international NGOs but a challenge to the national referral hospitals that are biomedical oriented and overwhelmed with emergencies and other referrals (Maulet et al., 2015). In this study, women report multiple visits to hospital for surgery and less than half had repeated surgeries. However, they were not residential in hospitals as they await the next surgery as opposed to the study in Mali, they stayed in their homes. Granted, these authors' latest contribution points to the length of the care process of fistula patients, suggesting that surgery is not a onetime episode since women undergo multiple surgeries. This care process after proper diagnosis may be long (Maulet et al., 2015). The study findings support this view.

Wall (2012b) has suggested that obstetric fistula is a neglected tropical condition. This study findings support this author's position, and even go further to demonstrate that neglect of obstetric fistula patients has led to the chronicity of fistula illness. The health system poor response to the fistula crisis has in part, contributed to the chronic nature of fistula illness in the country. The health system response is insufficient to cater for the needs. Many women's narratives included a missed diagnosis, lack of proper referral and inadequate information at the hospital they visited. Other facilities lacked fistula surgeons, and operating theatres. Some private facilities charged fees for screening tests that were unaffordable to the patients. In the composite pathway, three insufficiencies are demonstrated. First, the hospital is the most popular choice for women to seek treatment once they recognise symptoms of bowel incontinence. Yet many women do not obtain surgery upon contact with these hospitals, mostly for varied reasons, key amongst them being lack of capacity. Secondly, most women in my study ultimately delivered in hospital at the end of the obstructed labour. Perinatal nursing and midwifery care offers opportunity

to screen for fistula since most slough forms 4-14 days. This opportunity was only reported in few instances of fistula. Most women discovered by themselves the incontinence and amongst those who pointed this to the medical team, they did not get adequate information about this condition.

Third, although fistula corrective surgery may require several surgical attempts, some of the women in the composites pathway recorded up to 9 hospital visits spread over several years. This is not timely response to the needs of fistula patients. This study introduces new explanations to what characterises this chronic nature of fistula illness. As such, lack of other studies on the topic of chronicity of fistula illness limit chances of comparison.

Further, the findings suggest a systematic failure in the health care system to cater for the needs of women who present with obstetric fistula at the hospital. As such, the hospital is a key disperser of women to other forms of care providers; yet it is the most popular step taken by women when they realise symptoms of bowel and urinary incontinence. The multiplicity of hospital visits without proper referral and/ or surgery, the seeking of alternative avenues of healing including traditional medicine, prayer and healers in this study mimics the same phenomenon reported elsewhere in studies of health behaviour and therapy management in malaria in Kenya (Nyamongo, 2002).

Cost of fistula surgery and related expenses

All participants recruited in this study had obtained free corrective surgery. Provision of free surgery is important in enabling women to a positive realisation of their health seeking behaviour efforts since most are poor and cost was cited as an impediment in previous attempts to obtain surgery. In addition, one of the fistula centres facilitated patients with monetary reimbursements for transport to go back home after discharge. The provision of free surgery is common in all reported literature on fistula surgery in Africa, including Kenya (McFadden et al., 2011, Khisa et al., 2011) Tanzania (Mselle et al., 2011b),

Ethiopia (Williams, 2007, Donnelly et al., 2015), Malawi (Yeakey et al., 2011) Mali and Niger (Maulet et al., 2013) and Nigeria (Mohammad, 2007). In addition, a few programs also offer facilitation costs such as transport for the women to the fistula repair centres has been reported elsewhere with good result (Fiander et al., 2013, Mohammad, 2007). Mostly, the cost of surgery is sponsored by Non-Governmental organisations in partnership with government hospitals or dedicated private fistula repair centres.

Participants in this study who had been facilitated by transport to reach the facility recognised that the facilitation had taken the burden off them, especially for the mandatory visits for check-up after fistula surgery. This study findings support that of the Comprehensive Community Based Rehabilitation Program (CCBRT) in Tanzania that previously used mobile phones to transfer money to ambassadors who then assist the patients to cover transport costs while they seek treatment (Fiander et al., 2013). The Tanzanian project reported improved number of referrals for fistula surgery combined with free treatment owing to efficient mobile communication, training of the ambassadors and eliminated cost of transport. Granted, eliminating barriers such as lack of transport influences whether women will obtain fistula surgery or not, and improves post- surgery care and follow-up. In this study, some women did not attend the follow up visit on time as

Women's human rights

I argue that living with obstetric fistula, a shameful and stigmatised illness violates the human rights of women to optimal sexual and reproductive health as guaranteed by the International Conference for Population and Development (ICPD) of 1994 and the Constitution of Kenya 2010.

Secondly, the health system response to the needs of fistula patients in Kenya is inadequate, and at times delayed for decades converting their suffering to chronic illness state. The first inadequacy is demonstrated by the few numbers of women who obtain

surgery upon first and second instances if contact with the formal health system as presented in their composite health seeking behaviour pathway, and the hospital as a disperser of the participants to alternate forms of care. The second inadequacy is in terms of few women obtaining surgery against the huge backlog of women living with the condition in Kenya. The third and final category of inadequacy is the current approach to treating fistula illness that caters much to treat the physical incontinence but does little to treat the other injuries caused by the ‘obstructed labour injury complex’. After surgery, the holistic healing of fistula patients in physical, psychological, social and economic terms is not addressed.

7.3 Regaining normalcy and related outcomes

Fistula presents women with a crisis illness that severely disrupts their normal lives as they knew it. It interferes with their physical wellbeing and jeopardises their social interactions. Granted, it interferes with their gender roles of women as wives and mothers. Treating women for obstetric fistula thus starts them off on a path of recovery and regaining normal lives. In this section, the expectations of women of the treatment process and the extent to which they had regained normal lives in view of these expectations are presented. The results showed, as expected, the expectations from women of a cessation of the distressing symptoms of urine and or faecal incontinence. In addition, women demonstrated high levels of psychological trauma and were concerned about their sexual lives and reproductive capability in the period post - surgery.

7.3.1 Continence and ‘successful’ surgery outcomes

The importance of successful surgery is emphasised by all researchers who have conducted primary research on fistula (Young-Lin et al., 2015, Browning and Whiteside, 2015). Often, successful closure is alluded to in literature referring to closing the abnormal

opening between the vaginal cavity and urethra, bladder or rectum. In this way, successful surgery may also still be complicated by residual incontinence.

Women in this study experienced residual incontinence is a reality anticipated by existing literature on fistula (Browning, 2004, Wall and Arrowsmith, 2007). Women who have urethral involvement, a remnant small bladder, vaginal scarring and large diameter of a fistula are likely to have residual incontinence after closure of the fistula (Browning, 2006). In this regard, surgeons have increasingly researched and reported better and improved surgical skills to prevent residual incontinence in obstetric fistula patients at identified higher risk, such as use of a fibromuscular sling (Browning, 2004) or use of prostheses such as urethral plugs (Brook and Tessema, 2013, Goh and Browning, 2005)

Wall and Arrowsmith (2007) in their commentary note that while patients may be continent in 85% to 95% of the surgery cases, they may want more than just closure of the hole in their bladder and thus a 'continence gap' may remain among women who have undergone successful surgery. The authors reiterate that,

“Closure of the fistula is only the first step in the long process of restoring these women to health and successful re-establishing the disrupted social relationships that often result from a fistula and its stigmatizing aftermath”.(Wall and Arrowsmith, 2007):843

The authors further pointed out that 15% to 20% of women may experience residual incontinence (Wall and Arrowsmith, 2007). This residual incontinence may further complicate women's lives exhibiting reactions as those of living with fistula.

The findings of this study confirm two of these authors' predictions. First, women who are continent of urine and stool present a 'gap' in what constituted a normal life before fistula illness. This is caused by stigma, social isolation and exclusion against the backdrop of

complications of infertility, strained sexual relations, ruined marriages and psychological symptoms that linger post-surgery. Women thus face stressors on return to normal life beyond hygiene issues, touching on the core of the whole individual. The second finding in my study is women had residual incontinence alongside failed repair thus urinary and faecal incontinence symptoms after one year post surgery. These issues are unfortunately not the focus of the current practice of treating fistula patients in Kenya with focus on reparative surgery not being followed up by the other much needed holistic care and treatment of the individual women.

As the women have illustrated, their experiences of infertility, miscarriage, difficulty sexual relations and psychological stress are unattended to. Previous research on fistula has been scarce on this very issues, albeit a few occasional commentaries suggesting the need to treat the whole individual. Wall and Arrowsmith (2007) suggest that significant issues that should be the focus of treating the complete realm of fistula patients' illness should include treating to improve future fertility, restoring normal sexual relations, psychosocial injuries akin to post traumatic stress disorder, and returning the women to societies that may have previously treated them badly (Wall and Arrowsmith, 2007).

Given the substantive issues that linger in women's lives after treatment, fistula surgery is by no means the end but rather the start of treating women with obstetric fistula. Other areas such as healing psychological trauma and regaining normal reproductive function ought to be investigated, as suggested in the next two sections.

7.3.2 Healing Psychological Wounds

The moral properties of living with fistula constitute suffering and feelings of shame. Further, there are evidently psychological symptoms of the illness long after women have undergone surgical treatment. This is manifest threefold. First, women often narrate in retrospect the bad experience they had with the illness; clearly an issue unresolved in their

minds. They are thus unable to move on. The second instance is when women do not reveal the kind of illness they had a surgery, concealing illness identities to save face having borne a shameful illness. The third instance is seen in the other mentally stressful situations caused by the illness such as stigma, residual incontinence, divorce and separation and inability to bear children. These issues contribute to the individual mental anguish and suffering.

The study findings are in line with several authors who have reported poor mental outcomes in women who suffer obstetric fistula in Ethiopia (Zelege et al., 2013), Tanzania (Wilson et al., 2015) and Kenya (Khisra et al., 2011). In these three studies, researchers have considered mental health of fistula patients in the light of establishing the prevalence of depression symptoms, using available tools to measure such. This is a good trend in establishing the need for holistic care of fistula patients to include their mental health. Another study in Ethiopia further demonstrated that successful surgery improves the mental health of women although this improvement was little amongst those with residual incontinence on the GHQ-28 test used (Browning et al., 2007).

In Tanzania, Watt and colleagues recently developed and applied a pilot intervention for the psychological health of Tanzanian women admitted for fistula surgery (Watt et al., 2015). The psychotherapeutic intervention developed by a multidisciplinary team and patients input is based on cognitive behavioural therapy. A Trial run was conducted using a community nurse to deliver six individual counselling sessions on six topics namely 'recounting the fistula story; creating a new story; loss grieving and shame; strategies for coping; social relationships and planning for the future' with good result (Watt et al., 2015). Although the Tanzanian intervention study is beset for a bigger randomised control trial, it is a welcome move towards making fistula care more holistic. Similarly, one site in this Kenyan study had a residential counsellor who worked closely with women who were

admitted for fistula surgery and offered group counselling. However, there wasn't a provision for counselling after discharge to address subsequent patients' concerns and issues whilst in their communities. Community nursing and counselling approach would be a more feasible option for these participants, incorporating counselling interventions in the follow-up period after surgery. This gap is evidently presented in the narratives of women who expressed suicidal ideation and anxiety during follow-up period.

7.3.3 Fertility and regaining normal reproductive function

In this study, having lost previous pregnancies during fistula illness and inability to get a child in the period after surgery permeated women's tales of suffering. The infertility concern far outweighed the discharge instruction of having to wait two years to get a child. To the women and their husbands, it is an urgent concern to get a child, especially if they have no surviving child or have one child. Regaining normal reproductive capability is not only a concern for women who have tried getting a child but also to those who haven't tried but worry about future prospects of getting children. Categorically, fertility is an important issue recovery topic to women who have undergone fistula surgery.

Poor obstetric outcomes after fistula surgery have been reported in other studies. In a study conducted in Malawi, Wilson et al. (2011) reported that women who have undergone surgery for obstetric fistula may experience infertility, and poor pregnancy outcomes such as spontaneous abortion and perinatal mortality, and recommended further study into what causes these poor outcomes.

The greatest need is however to solve the existing problem amongst women who experience infertility as expressed by the study participants. The practice currently is that of treating women operatively and sexual health and fertility complications are not part of mainstream treatment for obstetric fistula. For instance, the World Health Organisation guiding principles for the management of obstetric fistula acknowledge infertility and

difficult sexual intercourse as a complication, but do not include these in the clinical care of patients, or as part of rehabilitation or reintegration (Gwyneth and Bernis, 2006).

In a study on healthcare providers' perspectives on social reintegration of fistula patients, Young-Lin et al. (2015) established that successful surgery, family acceptance especially from the husband, and future childbearing ability would influence a woman's reintegration after fistula surgery. The authors noted that in future pregnancies, the poor access to and prohibitive of caesarean section may lead to obstetric fistula recurring pointing out the need to improve reproductive health access for women post treatment (Young-Lin et al., 2015). Browning (2009) in a study conducted in Ethiopia, reported that women presented with repeat fistula in case they had prolonged labour before reaching the facility offering caesarean section or delivered vaginally.

The centrality of regaining normal reproductive function, the ensuing concerns about fertility in the immediate year postoperatively and concerns regarding accessibility for caesarean section deliveries in subsequent pregnancy are salient issues that must be addressed in a comprehensive fistula care program. Granted, there is need to support women for better outcomes during subsequent deliveries. However, for other women, the support would be to start with regaining their fertility.

7.4 Reintegration conceptual framework

As previously stated, no existing study comprehensively has focussed on the full range of reintegration outcomes of women post fistula repair in the physical, social, psychological and economic realms. Either, the disablers and enablers of reintegration for fistula patients in Kenya are yet to be identified. The conceptual framework I present thus identified, uniquely, the enablers of the reintegration process as being continent, fulfilling gender roles, regaining reproductive capability, marital stability, positive social interactions, economic independence and being able to obtain a skill or education. These can be

summarised in physical healing, material sustenance and resumption of disrupted life goals. On the other hand, the disablers of the reintegration process included incontinence, gender role insufficiency, infertility, divorce and separation, negative social interactions, dependence for sustenance and ill psychological health. Other studies have anticipated some of the reintegration needs presented here. The framework also identifies four outcomes of reintegration process for fistula patients as reintegrated, partially reintegrated, newly reintegration and not reintegrated.

Arrowsmith et al. (1996) use the term 'obstructed labour injury complex' to denote the need for treating women, in addition to closing the vaginal fistula, the ensuing stress incontinence, infertility, amenorrhea, foot drop and other mental and sociocultural problems caused by fistula. The authors asserted that obstetric fistula causes more harm than incontinence, and treating the incontinence is only the first step in healing the whole individual. This study goes further in pointing out what physical, psychological and socioeconomic factors may be prioritised in an integrated approach to care albeit in the context of fistula patients in Kenya.

A key issue identified by study participants was the need for psychosocial support after discharge into the community. Secondly, the participants faced many financial problems due to poor physical health and loathe their dependence for sustenance. These two issues have been focussed on in four comprehensive fistula treatment programs in Burundi (Tayler-Smith et al., 2013), Ethiopia (Williams, 2007), Nigeria (Mohammad, 2007) and Guinea (Diallo, 2009).

A comprehensive approach to fistula care carried out by the Gitega Fistula Centre in Burundi is described by Tayler-Smith et al. (2013). The model includes a social worker conducting psychosocial assessment of patients upon admission for rejection by family; employment constraints and financial repercussions. During hospital stay, in addition to

surgery and clinical care, the women are taught pelvic floor exercises. Individual counselling and group counselling is conducted and the women encouraged to participate in peer support activities like singing. Upon discharge, discharge counselling on how to obtain physical recovery and a method of family planning is offered. After the women are discharged, a social worker conducts a follow up on telephone to assess continence and psychosocial status and linkup with another organisation in case the woman is in distress. The authors report physiotherapy, social and economic rehabilitation and reintegration is vital and feasible though data were not available to assess the psychosocial and educational effects of this comprehensive model of care or the reintegration of women thereafter. Tayler-Smith et al. (2013) argue that while dedicated standalone centres may be expensive, they offer a supportive environment for holistic care and exclusive theatres offering opportunity to train other surgeons.

The model of providing comprehensive fistula care is a way of preparing the women to return to normal life, beyond the physical healing and regaining continence. Similar approaches are reported in Ethiopia (Williams, 2007) and Nigeria (Mohammad, 2007). The Hamlin fistula centre in Ethiopia conducts urologic surgery and reconstructive surgery, in addition to dedicated physiotherapy unit that deals with injuries such as foot drop, contractures and stress incontinence after reparative surgery. In addition, women who require reconstructive surgery are thereafter accommodated instead of having to use colostomy and ileostomy bags into their communities. This enables easier follow up (Williams, 2007).

The aspects of reintegration described by Diallo (2009) in a social immersion strategy program in Guinea aim at improving self-esteem, confidence and emotional health for women. The women receive both physical and psychological therapy and interpersonal

communication before being reintroduced into the community through host families. The women become community sensitisation ambassadors who advocate for fistula treatment.

The aspects of reintegration described by Mohammad (2007) suggests that an appropriate intervention should treat the physical, mental, social and economic consequences of fistula illness. The program in Nigeria, teaches literacy classes, agriculture, and income generating activities to women post operatively. Vocational activities like sewing and soap making, and business management skills. On leaving the centre, the clients are given a loan in kind or money to start an IGA. The clients were reported to have improved social standing, well empowered on economic and health fronts, and could bear children again. This is an example of a program that integrates health with development at the community level seeing that the two are inseparable; often women with fistula got the illness because of unfavourable structural and economic conditions.

The issues raised by study participants mimic some of those documented by other regarding the long term outcome of women who undergo fistula repair. Drew et al. (2014) reported improved quality of life of women 2 years post-operative. They identify the factors that imply good outcome as women's improved sense of freedom, mental peace and confidence in relationship with peers, improved community involvement and income generating activities. The women issues were financial, husband having other wives, desire for a husband and future children. Over half the women in study had no challenge on reintegration with one facing stigma. The study findings have elicited these factors as part of the reintegration process fistula patients, recognising that outcome falls along a reintegration continuum. Similarly, the aspects of reintegration proposed by Khisa et al (2016) suggest that the social and psychological impacts of obstetric fistula may manifest in a patient's life, even after the fistula is healed. In their article, they demonstrated that

although patients may applaud the surgery and physical continence, their euphoria may be short lived once they face realities of their new lives post-surgery.

Pope et al. (2011) established that women's ability to return to work and having family support as an important step in their reintegration, in addition to positive social interactions and a better status with time. The women identified the issue of residual incontinence as a problem. In this study, ability to go back to work is in relation to two key roles. First, the participants would like to work so as to fulfil their expected gender role of home maker and working the farm to produce food. Secondly, and true especially for those women who are single or separated, they would like to end the dependence for sustenance that ensues during fistula illness and endures a year on after fistula surgery. Residual incontinence is as source of mental anguish and diminished hope for women in my study, and is a likely to result in an outcome of still living with fistula and related suffering.

The study findings echo those of other studies on the mental health of fistula patients postop, and the ensuing dependence for sustenance. Further, the reintegration framework provides a basis for which evaluating social reintegration can be done, as suggested by Donnelly et al. (2015). In a study on the quality of life of Ethiopian women after fistula repair, Donnelly et al. (2015) reports that problems such as mental anguish, stigma, dependence and physical problems continued in some women, although all had a general sense of relief after the treatment. The authors suggest, for reintegration, community based counselling, income generating activities, community based follow up care, outreach to those who are still ill and development of a matrix for evaluating rehabilitation and social reintegration.

Browning and Menber (2008) reported the key drivers to perceived wellbeing of women 6 months postoperatively as being able to perform social activities like visiting friends or going to the market, restored sexual relations and fertility. Social desirability and regaining

reproductive function are interplay in my study as key components of regaining normalcy. However, the women in this study did not explicitly emphasise sexual relations, either because they don't deem it befitting to talk about it, or did not find it priority over the other issues they raised.

Being dry or continent of urine and faeces is one of the issues women focused on in response to their progress since surgery. Incontinence being their previous most recognisable symptom associated with the disease, the women measured their level of wellbeing with how well they are faring in bowel control. Continence or incontinence is therefore a significant marker by the women of their recovery. The issue of regaining continence is suggested in almost all studies conducted postoperatively (Nielsen et al., 2009, Browning and Menber, 2008, Dolan et al., 2008, Donnelly et al., 2015). However, in reporting their wellbeing study participants mentioned continence in relation with the persistence or clearing of hygiene challenges, ability to engage socially, find a job and other markers of reintegration. From the other studies' findings discussed in this section, some concepts that my participants put forth have been realised in other studies as key issues. Though contextual, the study findings demonstrate a close fit of what indeed is the reality of the lives of women with obstetric fistula post-surgery.

In recent times, at the end of my research, a mixed method research project was initiated in Uganda with the goal of developing a re-integration tool for fistula patients back to their communities (Byamugisha et al., 2015). The authors in their published protocol intend to develop and test a tool for reintegrating fistula patients. It will be of interest to sample the outcomes of the project once published for comparison with my study findings. Specifically, the extent to which the tool identifies similar enablers and disablers of reintegration identified in my framework. Secondly, the reintegration outcomes after using

the tool, in comparison to the four reintegration outcomes identified in my reintegration framework.

7.5 Contributions to current literature

This grounded theory study aimed at generating substantive theory and conceptual frameworks around obstetric fistula illness, which was sufficiently achieved in the study findings presented. The reintegration framework for fistula patients is novel as it encompasses a holistic approach to fistula care, taking into account enablers to be reinforced and disablers to be overcome for women to regain their normal healthy lives. In addition, the conceptual framework depicting the health seeking behaviour of fistula patients highlights the contextual and individual stressors and enablers to proper and prompt treatment and goes further to depict the chronicity of fistula illness.

Another unique contribution of this study is the focus on individual, contextual and macro-health system factors that interplay in the treatment pathways of fistula patients. The chronicity of fistula illness emphasis brings to light how reproductive health illnesses, when neglected, could play out and adopt a chronic career. This is the first comprehensive investigation of women's health seeking trajectories and such the findings are relevant to implementation of treatment programs in Kenya.

The substantive theory of regaining normalcy generated is an informed take on what constitutes fistula illness crisis, and how women respond to this crisis throughout health seeking and living with illness to regain normal life. The study findings thus contribute this integrated theory to implementation science and existing body of knowledge on obstetric fistula. There is no known existing model of regaining normalcy for fistula patients and this model would be soundly tested in intervention research.

7.6 Strengths and limitations

The study provides the most in-depth understanding of a process of regaining normalcy for fistula patient through the illness and treatment to reintegration using qualitative research methods.

The strength of this study is on the qualitative research methods utilised to give a nuanced and in-depth understanding of women's experiences of fistula illness and the process of reintegration. In addition, conducting community follow up studies in the home setting of participants obtained for us great cooperation and put participants at ease to talk freely. It also offered opportunity to interview married women's spouses who in most hospital based studies are likely to be missed out since they do not routinely stay throughout the fistula surgical camps.

A possible limitation is, in using narratives, the study generated information relying on women's memory to reconstruct their experience and this may have affected inaccurate recall, especially for women who may have lived with the illness for decades. However, probe questions, triangulation of sources and verification of earlier accounts were used to overcome this limitation and obtain credible and reliable data. Thus, the study provides sufficient evidence to suggest practice and policy changes in care of patients with obstetric fistula in Kenya.

The scope of this study was focused mainly on determining health seeking behaviour of obstetric fistula patients and strategies that improve reintegration of the women after surgery. Prevention of obstetric fistula, a vital component of the prevention-treatment-reintegration axis was not dealt with in this study. However, the narratives of context surrounding labour and childbirth of the index delivery suggests the possible issues that contributed to the formation of obstetric fistula.

7.7 Implications of the study findings

The objective study findings are representative pointers to the obvious dire situation of obstetric fistula care in Kenya. In these results lies the evidence for practice, policy and advocacy work on improving women's health. The findings in this study are the basis for the following suggested policy, training and research priorities on the broader area of fistula care and patient centred care.

7.7.1 Summary of situation in Kenya

Obstetric fistula is prevalent in 1% of women in Kenya (Kenya National Bureau of Statistics (KNBS) et al., 2015). The women develop obstetric fistula illness as early as 11 years of age (mean =23.2, median=22 years) and waste decades thereafter living with an illness that excludes them from leading normal social lives and participation in development. The illness causes incontinence hence stigma, isolation, depression, divorce, missed school and work opportunity. 47% of women living with fistula are depressed (McFadden et al, 2011). After surgery, women still experience physical poor health, residual incontinence, infertility, difficult sexual relations and divorce. In subsequent pregnancy, they need to be facilitated to deliver in a hospital through caesarean section.

The health seeking behaviour of fistula patients is characterised by a health system that is not responsive to their needs. Often, they lack appropriate facilities for screening, testing, diagnosis and surgical treatment. Fistula surgery is available to definitively cure women and as such 1200 women are operated each year in NGO, Government and private partnerships (African Medical and Research Foundation, 2011). This number of surgeries is too few in comparison to the estimated prevalence and backlog of cases.

Active groups outside of government who have been working on the fistula are multinational organisations like the UNFPA and NGOs such as AMREF, Freedom From Fistula Foundation and One by One. Dedicated fistula repair centres such as Gynocare

Fistula Centre and University teaching and referral hospitals such as Kenyatta National hospital and Moi Teaching and Referral Hospital and Kisii Level 5 hospital. Most women undergo more than one surgery with some having to undergo urinary diversion and ostomy.

After surgery the women then return to previously unsupportive social environments. They women depend on other people for sustenance due to discharge instructions that emphasise on avoiding strenuous activities. This is not compatible with economic activities such as farming and conducting business or hired labour as a source of income. Stigma, depression and mental symptoms, infertility and poverty persist. Reintegration should focus on holistic physical, social, psychological wellbeing of women post- surgery (Gwyneth and Bernis, 2006).

7.7.2 Recommendations

Based on study findings, the researcher recommends that in order for women and girls suffering from obstetric fistula to regain normal lives and participate in development, they should be treated using a holistic approach. In addition to being offered free surgery, they need long term counselling and psychotherapy, social and economic support, (education, trainings and business capital) and at times basic needs as food and housing if abandoned by family. Further occurrence of cases of obstetric fistula should be prevented in addition to clearing the current cases.

This research has policy implications on how care is delivered to women who suffer fistula. It requires the ministry of health to take action in terms of policy implementation and budget allocation; it requires fistula program design to incorporate prevention, improved health system response to fistula patients and reintegration as key components. Finally, changes are suggested to the practice of care of fistula patients from single treatment to a continuum of care into the communities with linkages and referrals for other

care aspects beyond the fistula repair facility – to include psychological, social and economic support.

Thus, this research falls in the domain of seeking to change the technical aspects of how fistula programmes are designed and implemented. Of specific focus and relevance is to the facilities treating fistula, health care providers participating in care of fistula patients, ministry of health and other ministries that support women’s health and financing, and nongovernmental agencies sponsor fistula treatment and advocacy.

The evidence presented here emanates from primary qualitative research that is transferable to women with fistula in similar contexts in the country. There is no contrasting or contradicting evidence on this issue as presented. In addition, there is evidence complementing my findings on the need for reintegrating fistula patients. Further, this research fills a knowledge gap in holistic management of fistula patients. Whilst the WHO expert guidelines as well as other fistula researchers have suggested reintegration that is context specific, there was little known on the subject in Kenya. The evidence presented in this research suggests a framework of how reintegration may be structured in the Kenyan context.

Specifically, the researcher recommends a change in the health system response to patients with fistula to hasten the time within which they obtain surgery, and to reduce barriers to patients’ health seeking efforts during fistula illness. As such, capacity building to get more fistula surgeons and facilities, midwifery training that incorporates screening for fistula in the perinatal period especially for women who have prolonged obstructed labour, and general health practitioners’ capacity to screen for and refer patients diagnosed with fistula appropriately and promptly are emphasised. In the immediate period, the level of awareness and skill in diagnosing fistula amongst frontline health workers ought to be determined through a national capacity assessment. These recommendations are

technically feasible with good planning and resource allocation and will be acceptable to the general public, women suffering from fistula and health care providers.

On the other hand, inaction means 1% of women in Kenya (prevalence of those who suffer obstetric fistula) may not be healed wholly, still live with fistula or its effects psychologically and socially; and not participate in development. There is a risk of GDP loss and not meeting the right to optimal reproductive health for the affected women.

Based on the research findings, a policy change for addressing the issue of obstetric fistula in Kenya is recommended. Government should prevent further occurrence of obstetric fistula through effective Emergency Obstetric Care (EmOC). Further, ministry of health should collaborate with university, NGOs and through other ministries like gender and social services in treating and providing reintegration services to women suffering from obstetric fistula. In this way, the continuum of care will start from prevention, treatment and rehabilitation will be put in place. The recommendations are divided into three main areas of policy, practice and further research.

7.7.2.1 Recommendations for Practice

Basing on the study findings, the following recommendations related to treatment of fistula patients are made:

1. Holistic approach to fistula care with sexual and reproductive health, regaining continence, fertility treatment, managing miscarriages and subsequent pregnancy.
2. Psychological counselling and therapy within and after surgical care, that continues during recovery period in the communities
3. Strengthened health system response to care for women with fistula illness. Includes prompt provision of screening, diagnosis and surgery.

4. Improving awareness and involvement of men in fistula prevention and treatment as part of involving the communities in care, and the after surgery care required.
5. Social and economic reintegration of fistula patients. The practice is in collaboration and partnership with actors beyond the fistula repair centre to include social welfare services and economic support.
6. Eliminating dependence through skill training and education as reclaiming disrupted life goals and regaining normalcy of girls and women.

7.7.2.2 Recommendations for Policy

Basing on the study findings, the following recommendations related to formulation, policy change and implementation of policy concerning fistula patients are made:

1. Treating women with obstetric fistula within a human rights lens and not just on humanitarian basis. This places the problem of fistula as priority alongside other illness that have previously dominated the national health budgeting.
2. Prompt and immediate treatment of obstetric fistula cases. The illness has turned into a chronic illness. Although surgery is ongoing, the numbers are too few and too late for a few women. A lot more women and girls live with fistula for decades and undergo suffering under an illness that is curable using current technology.
3. Prioritising training and surgical facility equipment is an urgent need for the country. This is with an aim of clearing the cases of women who are still suffering from obstetric fistula. Frontline health workers in maternal health should be equipped with skill to promptly diagnose and refer to treatment teams for care.

7.7.2.3 Recommendations for future Research

Basing on the study findings, the following recommendations related to further primary and implementation research on obstetric fistula are made:

1. Knowledge translation of these study findings to relevant audience, to include policy makers, general public and health care practitioners.
2. Adoption of an intervention research protocol based on the framework for holistic care for fistula patients.
3. Quality of life of women post fistula care in the long term, after 5 to 10 years of fistula treatment.
4. Feasibility of and perception of women towards urinary diversion surgery and other permanent corrective therapies of obstetric fistula surgery.

7.7.3 Implications of recommendations on economy and development

These recommendations have cost implications since the country's health system will have to spend more money if they adopt these recommendations for holistic care of fistula patients. However, if the country does not adopt these recommendations and run fistula treatment as is currently constituted, then the women's poor health will translate into lost productivity and failure to contribute to the national development. The opportunity costs for not achieving holistic healing for fistula patients will cost the country a forfeited income from about a quarter a million women estimated to be living with the condition in Kenya (Kenya National Bureau of Statistics (KNBS) et al., 2015).

However, the Kenya national development roadmap, Vision 2030 recognizes the importance of good health of the citizenship to the development of the country (Government of Kenya, 2012). Under the social pillar, investments in the people of Kenya

in terms of health, gender, youth and vulnerable groups are recognised. Existent flagship projects that could adopt and implement the changes in policy regarding care of women with fistula and rehabilitation is the ‘health care subsidies for social development to poor households’(Government of Kenya, 2012). Under this project, free fistula surgery can be afforded women with fistula, and those who are socially ostracised and economically unable to cater for their livelihood can be catered for in terms of small living stipends and subsidies until they are back on their feet. The second relevant flagship project under Vision 2030 is ‘mainstreaming research and development in health’ that would find the evidence presented by this research relevant and useful in informing national and county health policy makers.

The care of fistula patients in a holistic approach, as per these recommendations, is therefore in line with the country’s efforts to protect the right to health of its citizenry, and to sustainable development goals and other international health treaties to which we subscribe to. It is important to identify and review the existing health policy and rights documents relevant to obstetric fistula in Kenya.

7.7.4 Health policy and rights

Globally, within a human rights to health approach, the study recommendations on obstetric fistula fit within the components of Sustainable Development Goal 3 and 5 (United Nations Development Program, 2016). SDG 3 addresses ‘Good health and wellbeing for all at all ages’ and targets to reduce maternal mortality ratio. The conditions that reduce maternal mortality, including adequate obstetric care do reduce fistula too. The goal also aims at reducing mortality from non-communicable diseases and promoting mental health and wellbeing. Sustainable Development Goal 5 (SDG 5) aims to ‘achieve gender equality and empower women and girls’ through ensuring universal access to sexual and reproductive rights as agreed in ICPD and the Beijing Platform of Action.

Locally, the issue of obstetric fistula is relevant to and partly addressed by the Kenya National Reproductive Health Strategy 2009-2015 (Ministry of Health, 2009). The strategy recognises that in order to enhance provision of sexual and reproductive health services, there is need for crosscutting strategies such as health system strengthening, adequate human resource and improving basic infrastructure at health facilities (Ministry of Health, 2009). The one of the main objectives of the Kenya National Reproductive Health Policy 2007 is ‘to reduce the rates of maternal, perinatal and neonatal morbidity and mortality’ (Ministry of Health, 2007). In this regard the national strategy suggests strategies to ‘increase accessibility, acceptability, and utilisation of skilled attendance during pregnancy, childbirth and the post-partum period at all levels of the health care delivery system’ (Ministry of Health, 2009). Specifically, the National Adolescent Sexual and Reproductive Health policy 2015 recognises high rates of obstetric fistula among adolescents being caused by physiological maturity and delay in receiving emergency obstetric care at a health facility (Ministry of Health, 2015). One of the specific objectives is to ‘promote adolescent sexual and reproductive health ‘ and to ‘reduce early and unintended pregnancies’ (Ministry of Health, 2015). Basing on the definition of adolescents as persons aged between 10 and 19 years (Ministry of Health, 2015) my results show that 33.6% of participants were adolescents aged 11-19 years at the time when they developed obstetric fistula in Kenya.

In view of these three main policy documents in Kenya, the recommendations I make may be adopted and assimilated in the capacity building strategies to enact fistula reduction specific efforts without need for the country to develop new policies. These documents beset a basic framework within which, when implemented, obstetric fistula will be prevented and existing cases treated. Granted, they do not directly refer to strategies to reduce or eliminate obstetric fistula, which is one of the maternal morbidities emanating

from lack of skilled birth attendance, but nevertheless in their various strategies provide for this. This research provides evidence on how implementation of the existing policy documents will reduce further occurrence of fistulas, and treat existing ones. The reintegration of fistula patients after surgery is however not provided for in the three policy documents governing reproductive health in Kenya and suggested changes will have to be incorporated if the recommendations are adopted in part or wholly.

This approach of incorporating fistula care into existing policy is expedient in that it helps healing a significant proportion of the population who then return to participate in economically viable activities. This will also enable realisation of women's human rights, including the right to optimal health and universal access to sexual and reproductive health care as provided for by the International Conference on Population and Development (ICPD) (United Nations Fund for Population and Development, 1994), Sustainable Development Goals 3 and 5 and Kenya Vision 2030.

Greater collaboration and participation by all actors will ensure continuity in care and avoid fragmentation of effort. The disadvantage of such partnering and collaboration however, is greater negotiation needed and government may cede part of decision making and control to partners who jointly work with to eliminate fistula, as is common with partnerships and collaborations however, the greater advantage of eliminating fistula and improving the health of women in Kenya far outweigh this disadvantage.

This policy option is sustainable in preventing fistula and holistic treatment of existing cases. The government, by partnering with existing actors in the field of reproductive health, will be able to utilize their budgetary allocation to a better result. Collaborations will reduce fragmentation of efforts

7.7.5 Summary of Recommendations

This policy recommendation is a call to end the shame and stigma of obstetric fistula through strengthened health systems for maternal health. Based on existing research and current fistula care environment I recommend three main actions. First, Government prevents VVF through effective Emergency obstetric care. Secondly, government collaborates with university, NGOs and through other ministry like gender and development, to treat existing cases on an ongoing basis. Third, government and partners should provide reintegration services to women who have undergone reparative surgery.

The advantages of this approach helps healing the patients holistically and ensures that a significant population comes back to participate in economic viable activities. In doing so, Kenya will be moving towards realisation of human rights to optimal health. This approach will also ensure a greater collaboration and participation by all actors

This policy option is sustainable in preventing fistula and holistic treatment of existing cases. The government, by partnering with existing actors in the field of reproductive health, will be able to utilize their budgetary allocation to a better result. Collaborations will reduce fragmentation of efforts to provide care for fistula patients by the different actors.

The key actors to these recommended changes are first the members of the Kenyan public who first should be made aware of the illness and the provisions in place to prevent, treat and rehabilitate patients with obstetric fistula. Other organisations involved are the governments ministry of health, ministry of gender and social services, ministry of finance, planning and Kenya vision 2030, Non-governmental and donor organisations, national teaching and referral hospitals and fistula repair centres.

7.8 Conclusion

This study presents findings of the health seeking behaviour and reintegration of 121 patients with obstetric fistula from 30 counties in Kenya. I set out to develop a substantive theory on the overarching question on the experiences of patients as they sought healing for obstetric fistula illness. I used grounded theory methodology, a qualitative research approach to interrogate women's experiences of fistula illness and the process of reintegration, generating deep understanding of the issues women face in seeking reproductive health services. The use of grounded theory methodology to generate substantive mid-range theory that is grounded in the data offers a clear understanding of the process of holistic management of fistula patients.

I aimed to answer three key questions on main research questions, namely, 1) what key patterns of health seeking behaviour do women with obstetric fistula display in their quest for healing? 2) How do obstetric fistula patients cope with the illness? 3) What are the strategies that improve obstetric fistula patients' social reintegration?

I used narratives and in-depth interviews to collect data from women who had undergone obstetric fistula surgery from three fistula repair centres in Kenya over a period of nineteen months. I personally collected data alongside two research assistants and a third who translated the audio recordings into English and transcribed verbatim. The transcripts were then imported into NVIVO and coded.

The research yielded a number of findings. First, concerning patterns of health seeking behaviour, the chronicity of fistula illness is presented in the narratives of women who live with the illness for years to decades, presenting physical, hygiene and moral challenges. Fistula illness introduces a crisis in women's life begetting feelings of shame and being abnormal. To regain normalcy, women respond by reaching out to family and the formal health care system. A composite pathway of health seeking behaviour generated is

sequential, composed of seven key actors, with hospitals as key dispersers of women to alternative care providers. Health system failures are a key contributor to this pathway besides women's individual factors such as lack of knowledge about fistula illness and contextual situations such as support of family and peers. Thus, obstetric fistula manifests as a chronic illness in contrast to what is a curable maternal condition.

Concerning the manner in which patients cope with fistula illness, women rely on and draw from different sources of moral strength. Spousal support was specifically valued by women in addition to support from family members. The deviation from 'normal' bowel control, unstable marriage and supportive social networks challenge the women to attempt to regain 'normalcy'. Women therefore avoid social interactions, observe strict hygiene and avoid eating food or drinking that would lessen output.

Concerning the process of reintegrating fistula patients after reparative surgery, the process depends on the needs of the woman and the context within which she attempts to regain her previous normal life. After surgery, four possible outcomes of reintegration are presented, namely reintegration fully or partially back into their previous communities, not reintegrated or newly integrating away from previous social and family settings. The results were used to develop a conceptual framework of regaining normalcy of fistula patients. The framework suggests at each stage of the illness, areas that could be used to intervene at early diagnosis and treatment and reintegration stages of fistula illness.

One cannot safely assume that women will obtain treatment immediately after the occurrence of fistula, as the health system is too unresponsive to the needs of these women. Further, for those who obtain surgical treatment, one cannot assume that they resume normal life as before the illness. Often, women have to renegotiate their social situations and cope with discharge instructions that challenge their gender roles. Finally, women who suffer obstetric fistula still have other complications of the illness presenting

symptoms as mental, and infertility, and are anxious to resolve this in their regaining normal lives. The issues raised call for a multidisciplinary team in managing fistula patients, stretching from surgeons, nurses, social workers, occupational therapists and counsellors.

In general, the research succeeded in answering the overarching question, besides recording a few first and novel findings. For instance, the study findings suggest a comprehensive approach to reintegrating fistula patients, similar to the WHO suggested approach (Gwyneth and Bernis, 2006). In addition, four possible outcomes on the continuum of reintegration presented suggest need for further targeted interventions in fistula care programs. In addition, the categories that interplay during reintegration; physical health, psychological state, gender roles, disrupted biographies and dependence for sustenance, that were previously silent players in fistula care literature are clearly pointed out.

Secondly, complete documentation of women's narratives starting with the index labour, recognition of fistula illness until a woman is finally healed is another major contribution to science that this study has made, highlighting the bigger picture of fistula illness using qualitative research methods. In addition, a demonstration of the nature of fistula illness as a stigmatised and chronic maternal health condition is a first. As is, the chronic career of this illness could be reversed through targeted efforts aiming at modifying the health behaviour and treatment pathways of fistula patients.

Although I echoed previous researchers human rights lens in examining obstetric fistula, the originality of this research findings lie in the higher echelon analysis of the contextual issues surrounding obstetric fistula in Kenya. Adopting the stance of provision of safe delivery and healthcare as a human right offered a fresh yet startling view of the neglect women living with fistula face. Thus policy implications of this research are timely as the

country embraces the SDG 3 of ‘ensuring healthy lives and promoting wellbeing of all at all ages’ to make good this goal for women of reproductive age in Kenya. There is thus a strong recommendation to treat patients with obstetric fistula holistically, taking care of their biological, psychological, social and economic wellbeing and return to normalcy.

The key finding, grounded theory of regaining normalcy for fistula patients in Kenya and the associated conceptual frameworks thus laid basis on which I will build future research work.

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APPENDICES

Appendix 1: Participant Characteristics

A total of 121 participants (women with obstetric fistula) gave their narratives of the experience of health seeking behaviour during fistula illness. The demographic characteristics of 2 women whose narratives are included in the composite pathway were not obtained, and consequently 119 women's are presented.

Variable	Frequency (n)	Percent (%)	
Hospital Treated (N=121)	Gynocare	35	29.4
	Kenyatta National Hospital	56	45.4
	Kisii Level 5 Hospitals	30	25.2
Age in Years at time of study (N=121) Mean 33.2years Median 31.0 Mode 28 Range 40 (17-67)	15-19	9	7.6
	20-24	15	12.6
	25-29	27	22.7
	30-34	20	16.8
	35-39	13	10.9
	40-44	9	7.6
	45-49	7	5.9
	50-54	8	6.7
	55-59	3	2.5
	60-64	4	3.4
	65-69	1	0.8
	Don't know	3	-
	Not determined	2	-
Age in years at onset of fistula (N=118) Mean 23.2 Median 22 Mode 18 Range 44	10-14	10	8.4
	15-19	30	25.2
	20-24	31	26.1
	25-29	26	21.8
	30-34	5	4.2
	35-39	10	8.4
	40-44	2	1.7
	45-49	1	.8
	55-59	1	.8
	Don't know	1	-
	Not determined	2	-
	Level of Education (N=119)	None	15
Primary 1-4		9	7.6
Primary 5-8		56	47.1
Secondary		33	27.7
College		6	5.0
Total		119	100.0
No. of Surviving children	0	35	29.7

Variable	Frequency (n)	Percent (%)	
(N=118) Mean 2.0 Median 1.49 Mode 0 Range 9	1	26	22.0
	2	19	16.1
	3	11	9.3
	4	13	11.0
	5	5	4.2
	6	4	3.4
	7	3	2.5
	8	1	0.8
	9	1	0.8
	Total	119	100
Order of pregnancy when fistula occurred (N=118)	1 st	61	51.7
	2 nd	24	20.3
	3 rd	9	7.6
	4 th	11	9.3
	5 th	5	4.2
	6 th	2	1.7
	7 th	3	2.5
	8 th	1	0.8
	9 th	1	0.8
	10 th	1	0.8
	Total	118	100
Total Hospital Visits before surgery (N=119) Mean 4.13 Median 4 Mode 4 Range 9	1	3	2.5
	2	20	16.8
	3	23	20.2
	4	29	24.4
	5	21	18.5
	6	6	5.0
	7	8	6.7
	8	4	3.4
	9	3	2.5
	Total	119	100.0
Total No. of Surgeries (N=117) Mean 1.71 Median 1 Mode 1 Range 5	1	78	66.7
	2	15	12.8
	3	12	10.3
	4	6	5.1
	5	4	3.4
	6	2	1.7
	Total	117	100
Ever had fistula surgery prior to this one? (N=117)	Yes	41	35.0
	No	76	65.0
	Total	117	100.0
Where did you deliver the baby? (N=119)	Home	23	19.3
	TBA (Traditional Birth attendant)	4	3.4
	Hospital	92	77.3
Time in years lived with fistula Mean 8.9 Median 6.0 Mode 7.0 Range 39.0 (0.8-39.08)			
Number of children born	0	10	8.5

Variable	Frequency (n)	Percent (%)	
before fistula (N=118) Mean 2 Median 1 Mode 1 Range 9	1	59	50.0
	2	17	14.4
	3	10	8.5
	4	13	11.0
	5	2	1.7
	6	3	2.5
	7	1	0.8
	8	1	0.8
	9	2	1.7
	Total	118	100
Number of children born after fistula (N=118) Mean 0.64 Median 0 Mode 0 Range 6	0	80	67.8
	1	19	16.1
	2	9	7.6
	3	4	3.4
	4	4	3.4
	5	1	0.8
	6	1	0.8
	Total	118	100
Number of children who died/ stillbirth (N=117) Mean 0.81 Median 1 Mode 1 Range 6	0	46	39.3
	1	57	48.7
	2	9	7.7
	3	2	1.7
	4	2	1.7
	6	1	0.9
	Total	117	100
Where did you deliver the baby? (N=119)	Home	23	19.3
	TBA (Traditional Birth attendant)	4	3.4
	Hospital	92	77.3
	Total	119	100.0
If hospital what estimate time in hours before reaching hospital? (N=84) Mean 34.55 Median 17.50 Mode 48 Range 167	1	7	8.3
	2	3	3.6
	3	4	4.8
	4	2	2.4
	5	1	1.2
	6	2	2.4
	7	1	1.2
	8	3	3.6
	9	2	2.4
	11	2	2.4
	12	6	7.1
	13	2	2.4

Variable	Frequency (n)	Percent (%)	
	14	1	1.2
	15	1	1.2
	16	2	2.4
	17	3	3.6
	18	2	2.4
	20	1	1.2
	22	1	1.2
	23	1	1.2
	24	5	6.0
	26	1	1.2
	32	1	1.2
	48	14	16.7
	72	8	9.5
	84	1	1.2
	96	2	2.4
	120	1	1.2
	144	1	1.2
	168	3	3.6
	Total	84	100.0
County of Residence	Baringo	2	1.7
	Bungoma	4	3.4
	Busia	8	6.7
	Elgeyo Marakwet	5	4.2
	Embu	1	.8
	Homabay	2	1.7
	Kajiado	2	1.7
	Kakamega	3	2.5
	Kericho	2	1.7
	Kiambu	8	6.7
	Kirinyaga	1	.8
	Kisii	23	19.3
	Kisumu	1	.8
	Kitui	1	.8
	Machakos	6	5.0
	Meru	2	1.7
	Migori	1	.8
	Muranga	2	1.7
	Nairobi	13	10.9
	Nakuru	8	6.7
	Nandi	2	1.7
	Nyamira	1	.8
	Nyandarua	1	.8

Variable	Frequency (n)	Percent (%)
Nyeri	5	4.2
Siaya	2	1.7
Trans Nzoia	1	.8
Turkana	1	.8
Uasin Gishu	4	3.4
Vihiga	1	.8
West Pokot	6	5.0
Total	119	100.0

Appendix 2: Informed Consent Forms

HEALTH SEEKING BEHAVIOUR AND REINTEGRATION OF PATIENTS WITH OBSTETRIC FISTULA IN KENYA

Informed Consent Form Patients

Principal Investigator: Anne M. Khisa

Supervisors: 1). Professor Grace Omoni

2). Professor Isaac K. Nyamongo

Sponsors Name: Consortium for Advanced Training and Research in Africa (CARTA)

Part I: Consent Information Sheet

Introduction

Good morning/ afternoon. My name is Anne Khisa. I am a student at the University of Nairobi and as part of my studies I am carrying out a study on obstetric fistula. I would appreciate if you agree to participate in this study. Before you decide on whether to join the study or not, you will be provided with information regarding the study, a chance to ask questions and availed with a copy of this information sheet to keep.

Why is this study being done? The study seeks to investigate the kind of help that women seek while suffering from obstetric fistula and how they settle back into their communities after surgery. You are being asked to join the study as a patient who has undergone surgery for obstetric fistula.

What is expected of you? The study is intended to continue up to one year from now and will require two interviews. If you accept to be recruited in the study, you are expected to be available for a follow up interview. The researcher will therefore visit you at your home in a year from now. The study is being conducted in three hospitals in Kenya.

Are there any risks? If you join the study you may feel embarrassed, worried or anxious when answering questions from the study. There is no physical risk anticipated by participating in this study.

What benefit can you expect? While the facts we obtain from study might not help you directly, by participating, you provide useful information that will help treatment programs to provide care to patients with obstetric fistula in a better way.

Will you be paid to be in the study? The study does not offer any monetary or material benefits to participants.

You may refuse to be in the study. You are free to decline joining the study or to withdraw from this study at any point, and in such a case no penalty or disfavour will be shown towards you.

Confidentiality The information you give will be treated confidentially and your true identity shall not be revealed. The study does not offer any monetary or material benefit to the participants.

Withdrawal from the study You are free to withdraw from the study at any stage and are not bound to provide any reasons. During interviews, it is your right to stop the interview at any point in time or decline to answer some of the questions

Do you have any questions? Please feel free to ask any question you may have concerning the study.

Contact Information

Should you need to clarify your rights as a study participant please contact Professor Guantai, Chairman, KNH/UON Research Ethics committee, Tel 020 726300 P.O. Box 20723-00202 Nairobi, Email: knhuonerc@gmail.com

Or contact Dr Grace Omoni, Director School of Nursing, University of Nairobi, on Tel. 0202711250 P.O Box 19676 – 00202 Email: omonigrace@hotmail.com

Should you need any help or information regarding the study contact the researcher, Anne Khisa, Tel. 0724 348 661, P.O Box 14670-00100 Nairobi, Email: annekhisa@gmail.com

Part II: Certificate of Consent

Research participant

I have been invited to participate in the study on obstetric fistula in Kenya. The foregoing information has been read to me. I have had the opportunity to ask questions about it and have been answered to my satisfaction. I hereby declare that I have voluntarily opted to participate in the study.

Signature: _____ OR Thumbprint

Date: _____

Time: _____

Researcher

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

1. The information given shall be handled in a confidential manner
2. Their true identity will not be revealed
3. Their freedom to withdraw from the study will be guaranteed and no disfavour will be shown to them in case they decide to withdraw.

I confirm that the participant has had opportunity to ask questions about the study and have answered her correctly. The participant has freely and voluntarily accepted to participate in the study and has not been coerced into giving consent. The participant has been provided with a copy of this informed consent form.

Interviewers Name: _____ Signature: _____ Date: _____

Time: _____ Participant Code No. _____

TABIA YA KUTAFUTA AFYA NA KUWAUNGANISHA NA JAMII WAGONJWA WANAOGUA FISTULA ITOKANAYO NA UZAZI NCHINI KENYA

Fomu Ya Ridhaa Wagonjwa Wanaougua Fistula

Mkuu wa uchunguzi: Anne M. Khisa

Wasimamizi: 1 Professor Grace Omoni

2 Professor Isaac K. Nyamongo

Wadhamini: Consortium for Advanced Training and Research in Africa (CARTA)

muungano wa mafunzo ya juu na utafiti katika Afrika

Sehemu ya I: Karatasi ya Maelezo ya Idhini

Utangulizi

Habari za asubuhi / mchana. Jina langu ni Anne Khisa. Mimi ni mwanafunzi katika Chuo Kikuu cha Nairobi na kama sehemu ya masomo yangu mimi ninafanya utafiti juu ya fistula ya uzazi. Kabla ya kuamua iwapo kujiunga na utafiti au la, wewe utatapewa taarifa kuhusu utafiti huo, nafasi ya kuuliza maswali na utapewa nakala ya karatasi hii habari ya kuhifadhi.

Kwa nini utafiti huu unafanywa? Utafiti huu unalenga kuchunguza aina ya msaada wanawake hutafuta wakati wakiwa wagonjwa wa fistula itokanayo na uzazi, na jinsi wanavyorudi kukaa katika jamii zao baada ya upasuaji. Unaombwa kujiunga na utafiti huu kama mgonjwa ambaye amefanyiwa upasuaji kwa ajili ya fistula ya uzazi.

Yale yanayotarajiwa kutoka kwako: Utafiti huu unaazimiwa kuendelea hadi mwaka mmoja kutoka sasa na utahitaji kushiriki mahojiano kwa mara ya pili siku za usoni. Ikiwa wewe utakubali kujiunga na utafiti huu, unatarajiwa kujitolea muda wako wakati wa mahojiano ya ufuatiliaji kwa kipindi cha mwaka miezi tisa hadi mwaka mmoja ujao. Hivyo basi, mtafiti atakutembelea nyumbani kwako mwaka mmoja kuanzia sasa. Utafiti huu unaendeshwa katika hospitali tatu nchini Kenya.

Je kuna hatari? Unapojiunga na utafiti huu, unaweza kuhisi aibu, wasiwasi wakati ukijibu maswali ya utafiti huu. Haitarajiwi kuwa kuna hatari zozote za kimwili zinatokana na kushiriki katika utafiti huu.

Ni faida gani unaweza kutarajia? Habari tutakazopata kwa utafiti huu haziwezi kukufaidi moja kwa moja. Hata hivyo, taarifa hizi muhimu zitasaidia programu za matibabu kutoa huduma kwa wagonjwa wa fistula ya uzazi kwa njia bora zaidi.

Je utalipwa kwa kushiriki katika utafiti? Utafiti huu hautoi faida yoyote ya fedha au vifaa vyovyote kwa washiriki.

Unaweza kukataa kushiriki utafiti huu. Una uhuru kukataa kujiunga na utafiti huu au kuondoka kutoka utafiti huu wakati wowote, na katika hali kama hiyo hakuna adhabu au karaha itaonyeshwa dhidi yako. Kumbuka ya kwamba una uhuru kuyaacha mahojiano haya wakati wowote na haitakulazimu kutoa sababu zako za kuondoka. unawezapia kukataa kuyajibu baadhi ya maswali wakati wa mahojiano.

Usiri. Habari utakayotoa itashughulikiwa kwa siri na utambulisho wako wa kweli hautafichuliwa.

Je una maswali yoyote? Tafadhali jisikie huru kuuliza swali lolote unaweza kuwa nalo juu ya utafiti kabla ya kunipa idhini yako.

Maelezo ya mawasiliano

Je, unahitaji maelezo kuhusu haki yako kama mshiriki katika utafiti huu?

Tafadhali wasiliana na Profesa Guantai, Mwenyekiti wa Kamati ya Maadili ya Utafiti KNH/ UON Nambari ya simu: 020 726300 ext. 44102, Sanduku la posta: 20723-00202 Nairobi, Barua pepe: knhuonerc@gmail.com

Unaweza kuwasiliana na Dr Grace Omoni, mkurugenzi wa shule ya uuguzi, Chuo kikuu cha Nairobi, nambari ya simu 0202711250, Barua pepe: omonigrace@hotmail.com, sanduku la posta 19676 – 00202 Nairobi,

Je, unahitaji msaada au habari kuhusu utafiti huu? Tafadhali wasiliana nami mtafiti Anne Khisa Nambari ya simu: 0724 348 661, Sanduku la Posta: 14670-00100 Nairobi,

Barua pepe: annekhisa@gmail.com

Sehemu ya II: Hati ya Idhini

Nimealikwa kushiriki katika utafiti juu ya fistula itokanayo na uzazi nchini Kenya. Nimesomewa habari inayotangulia hapo juu na nimekuwa na nafasi ya kuuliza maswali kuhusu utafiti huu. Nimeridhika na jinsi maswali yangu yamejibiwa. Mimi ninatangaza ya kwamba nimeamua kujitolea kwa hiari bila kushurutishwa ili kushiriki katika utafiti huu.

Mshiriki Utafiti

Sahihi: _____ Au Alama ya Kidole Gumba

Tarehe: _____

Wakati: _____

Mtafiti

Mimi nimemsomea mshiriki uwezo karatasi hii ya habari kwa usahihi, na kwa kadri ya uwezo wangu nimehakikisha kuwa mshiriki anaelewa kuwa yafuatayo yatafanyika:

1. Maelezo yatakayotolewa yatashughulikiwa kwa njia ya siri
2. Utambulisho wake wa kweli hautafichuliwa
3. Uhuru wake wa kujiondoa kutoka utafiti utahakikishwa na hakuna adhabu au karaha itakayo onyeshwa dhidi yake.

Ninathibitisha kuwa mshiriki amepewa nafasi ya kuuliza maswali juu ya utafiti huu na kuwa nimemjibu kwa usahihi. Mshiriki amekubali kushiriki katika utafiti kwa hiari yake na hajashurutishwa vyovyote vile ili kutoa idhini. Mshiriki amepewa nakala ya fomu hii ya ridhaa.

Jina la Mhoji:

_____ Sahihi: _____ Tarehe: _____

Wakati: _____ Nambari ya kificho ya Mhojiwa _____

Nambari ya kificho ya Stesheni _____

Appendix 3: Narrative Guide for Exploring Health Seeking Behaviour

HEALTH SEEKING BEHAVIOUR AND REINTEGRATION OF PATIENTS WITH OBSTETRIC FISTULA IN KENYA

Code No [__|__|__|__|__] Site No [__|__] Recorder No _____

Date: _____ Time: Start [__|__|__|__] Stop [__|__|__|__]

Narrative Guide I: Patients

Introduction

Good morning/ afternoon. My name is _____. I am carrying out a study on obstetric fistula. The study seeks to investigate the kind of help that women seek while suffering from obstetric fistula and how they settle back into their communities after surgery. As a patient who has undergone surgery for obstetric fistula, I would like to ask you some questions on this topic. Please feel free to answer honestly and provide as much detail as possible to the best of your memory. The conversation will be recorded for transcription later on though I will take some notes during our conversation. Can I proceed?

Record verbally the Code No and Serial No on the voice recorder.

1. Tell me about the illness you have had. What were the first symptoms? What did you think when you noticed these symptoms? What caused those symptoms? What did you do?
2. Describe the circumstance around which you developed this condition? *Probe for labour and childbirth experience, skilled birth attendants, TBA*
3. How did you get to know you had this condition?
4. What did you do when you realised you had this condition?
5. Who was the first person in your family did you share information about your illness? What reasons made you share with this person? Are there other people you shared with next and what are the reasons for this?
6. Are you able to recall the people you consulted? Who among these was the first person you sought help from? Who did you seek help from next? What help did they give you? What did you do next? *(Probe from first to last point of person's participant sought help from).*
7. Describe the help you received from these individual(s)? What help did this individual(s) accord you? What additional help would you have liked to receive?
8. Explain the reasons that led to your choice of the individuals / places you sought help from? *Probe for convenience, beliefs, cultural requirements, authenticity of provider, health and other reasons. Ask this question for all providers mentioned by participant.*
9. During the illness what are the ways that you used to cope with the illness?
10. Where do you routinely/ normally go or whom do you consult when you are ill from other illnesses?

Dodoso La Maswali ya Wagonjwa Wanougua Fistula

Mwongozo Wa Simulizi I (Mgonjwa)

Utangulizi

Habari za asubuhi / mchana. Jina langu ni _____. Mimi ni mwanafunzi katika Chuo Kikuu cha Nairobi na kama sehemu ya masomo yangu mimi ninafanya utafiti juu ya fistula ya uzazi. Utafiti huu unalenga kuchunguza aina ya msaada wanawake hutafuta wakati wakiwa wagonjwa wa fistula itokanayo na uzazi, na jinsi wanavyorudi kukaa katika jamii zao baada ya upasuaji. Tafadhali eleza kwa kina, na kwa kadiri ambavyo unaweza kukumbuka, bila kuwa na uoga wowote. Kama nilivyo kueleza hapo awali, una uhuru wa kutamatisha mahojiano haya wakati wowote tunapoendelea na mazungumzo iwapo utahisi huwezi kuendelea tena. Wakati wa mahojiano, tutatumia kinasauti ili tuyachapishe mahojiano haya, hata hivyo, mimi nitakuwa nikiandika kwa ufupi tunapoendelea na mahojiano. ***Je tunaweza kuendelea?***

Maswali

1. Hebu nieleze kwa kina kuhusu ugonjwa huu/ uliokuwa nao. Je, ni dalli na maumivu gani uliohisi? Je, ulipoona dalili hizi, ulikuwa na mawazo gani? Ulifikiri nini? Ni nini kilichosababisha dalili hizi? Je, ulifanya nini?
2. Elezea mazingira ambayo hali hii ilitokea? (Peleleza ajriba ya uzazi wa mtoto na matukio yaliojiri alipojifungua, mhudumu aliyemzalisha)
3. Elezea jinsi ulivyogundua una hali hii ya fistula?
4. Je, ulifanya nini ulipogundua ya kwamba una hali hii?
5. Ni mtu yupi wa kwanza katika familia yako uliyemweleza kuhusu hali yako? Je, ni kwa sababu gani ulimweleza yeye kwanza? Je, kuna watu wengine uliowaelezakuhusu hali hii katika familia yako? Je, ni kwa sababu gani uliweleza wao?
6. Je, unaweza kumbuka watu au wajuzi ulienda kwao kupata msaada wa matibabu? Hebu nitajie wale uliowatembelea? Ni nani kati yao uliyemtembele wa kwanza? Ni msaada gani aliokupa? Ni nani aliyefuatia? Ulifanya nini baada ya hapo? Elezea ulikoenda na watu ulioshauriana nao ili kupata msaada wa matibabu tangu mwanzo hadi sasa ulipofika hospitalini? (*Peleleza tangu mwanzo hadi muuguzi wa mwisho aliyehudumia mgonjwa huyu*)
7. Mbona wewe ulichagua kwenda kwa mtu huyu wa kwanza uliyeshauriana naye? Je, ni sababu gani uliowatembelea wale wahudumu walio fuatia? *Eleza sababu ambazo zilifanya uwachagua wale wahudumu au mahali ulikoenda kutafutatiba kwao? Peleleza kuhusu urahisi wa kupata huduma kwa ajili ya umbali, imani ya mhojiwa, mila ya uponyaji, uhalisi wa mhudumu, sababu za kiafya, na mengineyo. Uliza swali hili kuhusu wahudumu wote wa afya waliotajwa.*
8. Ni msaada gani uliyopewa na watu hawa uliowataja? Je, kwa maoni yako, msaada huu ulitosha?
9. Ni mbinu/mikakati gani ulitumia kukabiliana na hali iliyoletwa na ugonjwa huu?
10. Je, ni wapi unapokwenda kwa kawaida kutafuta matibabu ya magonjwa mengine?

Serial No _____

Patients Demographic Profile

To be filled in after narrative.

Code No [__|__|__|__|__] Site No [__|__] Recorder No _____

Date: _____ Time: Start [__|__|__|__] Stop [__|__|__|__]

Introduction

Good morning/ afternoon. My name is _____. I am carrying out a study on obstetric fistula. The study seeks to investigate the kind of help that women seek while suffering from obstetric fistula and how they settle back into their communities after surgery. As a patient who has undergone surgery for obstetric fistula, I would like to ask you some questions on this topic. Please feel free to answer honestly and provide as much detail as possible to the best of your memory. The conversation will be recorded for transcription later on though I will take some notes during our conversation. **Can I proceed?**

Section I: Demographic/ Social data

1. How old are you now? Age in completed year's (numerals) [__|__|__]
2. What is the highest level of education you have attained? (tick one)
 None primary 1-4 primary 5-8 secondary 1-4
 Technical institute College University
3. How many children do you have: (numerals)
 - a) Alive? _____
 - b) How many were born before the fistula? _____
 - c) How many were born after the fistula? _____
 - d) Died? _____

Section II: History of Fistula Occurrence

4. Number of pregnancy when the fistula occurred? _____ (record in numerals e.g. 1, 2, 3 etc.)
5. How old were you when fistula occurred? (age in years, numerals) _____
6. How long did you live with fistula before treatment? (numerals)
Years _____ months _____
7. Have you had another VVF surgery prior to this one?
 Yes No (go to Q 10)
8. If yes, how long ago was the surgery done? (numerals)
Years _____ months _____
9. What was the outcome of the surgery? (tick one only)
 I was healed completely I am still incontinent of urine
 I still have psychological symptoms
 I still experience pain other (specify) _____
10. In the delivery and labour that caused the current illness, where did you deliver the baby?
 Home TBA Hospital other _____ (specify)
11. If hospital, what is the estimate time in hours you spent in labour before reaching hospital? _____
12. What is the distance in Kilometres from your current home to the nearest health centre or mobile clinic station?
 0-1 2-5 6-10 11-20 21-50 Above 50

13. What was the distance in Kilometres from your home to the nearest health centre or mobile clinic station when the fistula occurred?

- 0 -1 2-5 6-10 11-20 21-50 Above 50

14. What is the distance in Kilometres from your current home to the nearest district hospital?

- 0 -1 2-5 6-10 11-20 21-50 Above 50

15. What was the distance in Kilometres from your home to the nearest district hospital when the fistula occurred?

- 0 -1 2-5 6-10 11-20 21-50 Above 50

16. During your hospital stay which of the following services have you received? (*Tick all mentioned*)

- Counselling Exercises Physiotherapy

- Surgery and clinical care Nursing care Health education

Others (specify) i) _____

ii) _____

iii) _____

Section IV: Locator information (*to be filled in simultaneously with index J*)

When you get discharged from hospital during your current visit, where is your residential address going to be? County _____ District _____

Location _____ Sub-location _____ Village _____

To be recorded in Index J only: Kindly provide us with your **Telephone contacts** for the researcher to contact you for the follow up interview? **THANK YOU.**

**TABIA YA KUTAFUTA AFYA NA KUWAUNGANISHA NA JAMII WAGONJWA
WANAOGUA FISTULA ITOKANAYO NA UZAZI NCHINI KENYA**

Sehemu ya I: Takwimu za Kidemografia

Utangulizi

Habari za asubuhi / mchana. Jina langu ni _____. Mimi ni mwanafunzi katika Chuo Kikuu cha Nairobi na kama sehemu ya masomo yangu mimi ninafanya utafiti juu ya fistula ya uzazi. Utafiti huu unalenga kuchunguza aina ya msaada wanawake hutafuta wakati wakiwa wagonjwa wa fistula itokanayo na uzazi, na jinsi wanavyorudi kukaa katika jamii zao baada ya upasuaji. Tafadhali eleza kwa kina, na kwa kadiri ambavyo unaweza kukumbuka, bila kuwa na uoga wowote. Kama nilivyo kueleza hapo awali, una uhuru wa kutamatisha mahojiano haya wakati wowote tunapoendelea na mazungumzo iwapo utahisi huwezi kuendelea tena. Wakati wa mahojiano, tutatumia kinasa sauti ili tuyachapishe mahojiano haya, hata hivyo, mimi nitakuwa nikiandika kwa ufupi tunapoendelea na mahojiano. ***Je tunaweza kuendelea?***

1. Je, Una umri wa miaka mingapi sasa?
2. Je, ni kipi kiwango cha juu zaidi cha elimu ambacho umehitimu?
 Hakuna Shule ya msingi 1-4 Shule ya msingi 5-8
 Shule ya sekondari Chuo cha kiufundi Chuo kikuu.
3. Je, _____ una _____ watoto _____ wangapi:
walio hai? _____
Waliozaliwa kabla ya fistula? _____
Waliozaliwa baada ya fistula? _____
waliokufa? _____

Sehemu ya II: Historia ya Matukio ya Fistula

4. Je, mimba hii ilikuwa ya ngapi wakati fistula ilitokea? _____ (*Rekodi katika tarakimu kwa mfano 1, 2, 3 nk*)
5. Je, ulikuwa na umri gani wakati fistula ilitokea?

6. Je uliishi kwa muda wa miaka mingapi ukiwa na huu ugonjwa wa fistula kabla ya matibabu?
Miaka _____ Na Miezi _____
7. Je, umewahi kufanyiwa upasuaji wa ugonjwa wa fistula kabla ya upasuaji huu wa hivi majuzi hapa _____?
 Ndio La (nenda nambari 10)
8. Ikiwa ndio, upasuaji huo ulifanywa wakati gani kuanzia sasa?
Miaka _____ Na Miezi _____
9. Je, matokeo ya upasuaji huo yalikuwa yapi?
 Nlipona kabisa Bado nahisi dalili za kutokwa na mkojo au haja kubwa
 Bado nina maumivu ya uchungu Bado nina mawazo mengi kuhusu ugonjwa huu uliyonipata Jingine (Eleza) _____
10. Je, katika ile mimba iliyosababisha fistula uliyotibiwa kwayo sasa, wewe ulijifungulia wapi yule mtoto?
 Nyumbani Mkunga wa kienyeji Hospitalini Nyingine

11. Ikiwa ni hospitalini, je hospitali hii ipo umbali wa kadri **masaa** mangapi unaposafiri?

12. Je, unaishi umbali wa Kilomita ngapi kutoka kituo cha afya kilicho karibu / kituo cha kliniki ya _____ kuhama?
 0 -1 2-5 6-10 11-20 21-50
13. Je, wakati ulipata huu ugonjwa wa fistula ya uzazi, ulikuwa unaishi umbali wa Kilomita ngapi kutoka kituo cha afya kilicho karibu / kituo cha kliniki ya kuhama?
 0 -1 2-5 6-10 11-20 21-50
14. Je, unaishi umbali wa Kilomita ngapi kutoka hospitali ya wilaya?
 0 -1 2-5 6-10 11-20 21-50
15. Je, wakati ulipata huu ugonjwa wa fistula ya uzazi, ulikuwa unaishi umbali wa Kilomita ngapi kutoka hospitali ya wilaya?
 0 -1 2-5 6-10 11-20 21-50
16. Wakati umekuwa hospitalini humu, ni huduma gani ambazo umepokea kati ya zifuatazo?
(Weka alama ya vema kwa zote zilizotumika)
 Ushauri nasaha Mazoezi viungo vya mwili upasuaji na
huduma ya kitabibu Huduma ya uguzi huduma ya elimu ya afya
- Nyinginezo (*taja*)
- i) _____
- ii) _____ iii)
- _____

Sehemu ya III: Maelezo kwa ajili ya kumpata mshiriki

Tafadhali eleza anuani yako ya makazi unayoelekea baada ya kuruhusiwa kwenda nyumbani

Kaunti ya _____ Wilaya ya _____
Lokesheni _____ Lokesheni ndogo _____ Kijiji _____

Sehemu hii ijazwe mtawalia na Index J: Tafadhali niarifu **nambari ya simu** yako kwa ajili ya mtafiti kuwasiliana nawe wakati wa mahojiano ya pili ukiwa nyumbani?

ASANTE

Appendix 4: Narrative Guides for Exploring Reintegration of Fistula patients

HEALTH SEEKING BEHAVIOUR AND REINTEGRATION OF PATIENTS WITH OBSTETRIC FISTULA IN KENYA

Narrative Guide II (Patient Follow Up at 6-9 months)

(Record in index J: Participant Code, Geographical location, contacts at time of interview.)

Introduction

Good morning/ afternoon. My name is _____ and I am a student at the University of Nairobi. We have come to visit you in your home following your surgery for obstetric fistula illness. You are being visited as one of the participants who were recruited into the study in its first phase, and as one who had agreed to a follow up visit and interview upon joining the study. The study information and participation remains the same as explained to you in your written consent information form. Do you have any questions regarding your participation in this study, or the information I have given you?

We would like to have an interview with you to discuss how you have progressed since then. I would like to ask you some questions on this topic. Please feel free to answer honestly and provide as much detail as possible to the best of your memory. The conversation will be recorded for transcription later. I also will take some notes during our conversation. Kindly allow me to proceed.

1. How would you describe your physical condition after the surgery? *Probe for ability to perform household chores, business or farming, employment, presence of leaking of urine, faecal matter or continent, other physical symptoms like pain.*
2. Explain your interactions with your previous friends and peers since discharge from hospital. *Probe for ability to mingle and interact freely, acceptance, isolation, labelling, stigma, participating in gender roles, social events, women groups.*
3. Describe how the members of your family perceive and treat you since your surgical treatment? *Probe for social interaction, acceptance, stigma, participation in gender roles and activities*
4. Describe how the members of your community perceive and treat you since your surgical treatment? *Probe for social interaction, acceptance, stigma, participation in gender roles and activities*
5. State the relationship you have had with your husband/ spouse since the surgery? *Probe: How would you rate the level of interaction with him comparing with the period prior to surgery? Probe if couple have resumed sexual intercourse, feelings of normality or abnormality. if unmarried; probe dating and subsequent marriage options*
6. What was the effect of this surgery to you psychologically? Socially? *How well does the outcome of the surgery meet your expectations in the period prior to surgery?*
7. What kind of help have you received since your discharge that has helped you settle back into the community? *Probe for services e.g. counselling, social worker visits, infertility*

treatment, family planning, treatment for STI, other reproductive health services, skill training, vocational training, and economic support.

8. How sufficient has this help been in helping you settle back in your marital home/ natal home and community?
9. In your opinion, what other help/ service would you have liked to receive besides what you have mentioned above?
10. Describe any efforts, campaigns or organisations you are aware of in this community that work against obstetric fistula? *Probe: In your opinion is the service offered by this organisation(s) adequate? What additional information or service would you like them to offer? List all mentioned.*

Narrative Guide III (Patient Follow Up at 1 year Post- op)

(Record in index J: Participant Code, Geographical location, contacts at time of interview.)

Introduction

Good morning/ afternoon. My name is _____ and I am a student at the University of Nairobi. We have come to visit you in your home following your surgery for obstetric fistula illness. You are being visited as one of the participants who were recruited into the study in its first phase, and as one who had agreed to a follow up visit and interview upon joining the study. The study information and participation remains the same as explained to you in your written consent information form. Do you have any questions regarding your participation in this study, or the information I have given you?

We would like to have an interview with you to discuss how you have progressed since then. I would like to ask you some questions on this topic. Please feel free to answer honestly and provide as much detail as possible to the best of your memory. The conversation will be recorded for transcription later. I also will take some notes during our conversation. Kindly allow me to proceed.

1. Given where you were 1 year ago, tell me what has changed?
2. Kindly narrate how your life has been since we talked in the last six months? *Probe for their wellbeing, physical health, urinary/faecal continence, other physical symptoms like pain*
3. How would you describe your physical condition? *Probe ability to perform daily activities, household chores, work, business, farming, employment.*
4. What instructions were you given upon discharge? To what extent did you follow these instructions?

Probe i) for 6 months abstinence; avoiding physically strenuous work; exercising pelvic muscles ; family planning; delivery in hospital for subsequent pregnancy

Probe ii) what challenges have you experienced in following these instructions?

5. As an individual, what problems/ concerns do you have regarding your reproductive health? *Probe for issues to do with FP, ANC, childbirth, infertility, others mentioned*

6. What have you experienced from those you interacted with socially? *Probe for family members, Peers and friends, Husband, Community members*
7. For you to say 'people have fully accepted me' what have you seen/ experienced?
8. In your opinion, what does it mean to be well adjusted back to your normal life?
9. Describe how this illness has affected you or disturbed your life goals?
10. Kindly express any additional comments or information you have concerning the illness of fistula?

Appendix 5: In-depth Interview Guide (Family Members)

HEALTH SEEKING BEHAVIOUR AND REINTEGRATION OF PATIENTS WITH OBSTETRIC FISTULA IN KENYA

In-Depth Interview Guide (Family Member)

(To be recorded in index J: Participant Code No, Geographical location- District, Location, Sub-location, and Village at time of interview.)

Code (Interviewee) _____ / Code (patient) _____ (record on tape/ notebook)

Introduction

Good morning. My name is Anne and I am a student at the University of Nairobi. We have come to visit you in your home following the surgery of your wife for the obstetric fistula illness. You have been asked and consented to participate in the study as the spouse/ family member of _____ (name), one of the participants who were recruited into the study. We would like to have an interview with you to discuss how her illness occurred, the period up to treatment and her progress after discharge from hospital. I would like to ask you some questions on this topic. Please feel free to answer honestly and provide as much detail as possible to the best of your memory. The conversation will be recorded for transcription later on though I will take some notes during our conversation.

Can I proceed?

Health Seeking Behaviour

1. How did your wife's/ daughter/ sister's obstetric fistula illness arise? *Probe for cause and context of the delivery that caused vaginal fistula, the people who assisted her during labour and delivery.*
2. How did the illness affect you? *Probe psychological effects, social, economic, marital stability and effect on the family*
3. How did you cope with these effects? *How did this change after her surgery?*
4. Did you receive any information regarding your daughter/ sister/ daughter inlaws condition? What kind of information did you receive? *In your opinion, how adequate was this information? What specific information would you have liked to receive regarding her condition?*
5. Try to recall the period before the surgery. What help did you offer the patient when she was seeking treatment? *Probe for the people they consulted and the reasons for consulting them.*
6. Describe the kind of help sought by women suffering from obstetric fistula? *Probe for the people they are more likely to consult and the reasons for consulting them.*

Reintegration

7. What help have you offered her since her discharge from hospital?
8. Focusing on the period after surgery, explain how the surgery affected her marital relationship with her husband/ Spouse? *Probe for reunion, divorce, separation, marrying another wife, abandonment, probe to compare the situation before surgery and before illness?*
9. Since the survivor had the corrective surgery, what is your perception towards her? *Probe for level of interaction, do you view her as ill, spoilt, labelled, blemished, etc*

10. Explain any incident/ circumstance that may prevent a survivor from reuniting with her family after surgery? *Probe for stigma, poverty, taboos and beliefs, others.*
11. To what extent has the woman resumed her normal life and settled back into the community? *Probe for resuming normal activities and gender roles, scope of social interactions.*
12. In your opinion, what kind of help do women need to reintegrate after surgery? *Probe for any of reintegration services*

Appendix 6: In-depth Interview Guide (Health care providers)

HEALTH SEEKING BEHAVIOUR AND REINTEGRATION OF PATIENTS WITH OBSTETRIC FISTULA IN KENYA

In-Depth Interview Guide (Key Informant)

Code _____ Site Number _____ Serial number _____
(record on tape)

Introduction

Good morning/ afternoon. My name is _____. I am carrying out a study on obstetric fistula. The study seeks to investigate the kind of help that women seek while suffering from obstetric fistula and how they settle back into their communities after surgery. As a healthcare provider to patients who have obstetric fistula illness, I would like to ask you some questions on this topic. Please feel free to answer honestly and provide as much detail as possible to the best of your memory. The conversation will be recorded for transcription later on though I will take some notes during our conversation. ***Can I proceed?***

Questions

1. When a woman with obstetric fistula consults you, what help do you offer her? *Probe for treatment options, medicines, healing rituals, referral chains.*
2. Describe the services available to patients with fistula in this region? *Probe for counselling, treatment/ surgery, rehabilitation, reintegration, financial support, training, awareness campaigns.*
3. Describe the reintegration services offered to fistula patients in this facility? *Probe for availability and adequacy of the services mentioned*
4. In your opinion are these services sufficient to aid the reintegration of fistula patients?
5. What other services are necessary for reintegration of fistula patients? *Probe for best approach for reintegration. Probe for counselling, treatment/ surgery, rehabilitation, reintegration, financial support, training, awareness campaigns.*
6. In your opinion, to what extent do women who suffer this condition reintegrate back after surgery? *Probe to further illustrate answer, challenges faced and factors that help reintegration.*

THANK YOU

**TABIA YA KUTAFUTA AFYA NA KUWAUNGANISHA NA JAMII WAGONJWA
WANAOGUA FISTULA ITOKANAYO NA UZAZI NCHINI KENYA**

Mwongozo Wa Mahojiano Ya Kina Na Mhojiwa Muhimu

Nambari ya kificho ya Mhojiwa _____ Mfululizo wa nambari _____

Nambari ya kificho ya Stesheni _____

Utangulizi

Habari za asubuhi / mchana. Jina langu ni _____. Mimi ni mwanafunzi katika Chuo Kikuu cha Nairobi na kama sehemu ya masomo yangu mimi ninafanya utafiti juu ya fistula ya uzazi. Utafiti huu unalenga kuchunguza aina ya msaada wanawake hutafuta wakati wakiwa wagonjwa wa fistula itokanayo na uzazi, na jinsi wanavyorudi kukaa katika jamii zao baada ya upasuaji. Tafadhali eleza kwa kina, na kwa kadiri ambavyo unaweza kukumbuka, bila kuwa na uoga wowote. Kama nilivyo kueleza hapo awali, una uhuru wa kutamatisha mahojiano haya wakati wowote tunapoendelea na mazungumzo iwapo utahisi huwezi kuendelea tena. Wakati wa mahojiano, tutatumia kinasa sauti ili tuyachapishe mahojiano haya, hata hivyo, mimi nitakuwa nikiandika kwa ufupi tunapoendelea na mahojiano.

Je tunaweza kuendelea?

Maswali

1. Wakati mwanamke anayeugua ugonjwa wa fistula ya uzazi anapokuja kukushauri, ni msaada gani wewe humpa? *Peleleza uchaguzi wamatibabu, dawa, mila uponyaji, minyororo ya rufaa.*
2. Elezea huduma inayopatikana kwa wagonjwa na fistula katika mkoa huu? *ushauri nasaha, matibabu / upasuaji, ukarabati, kuwaunganisha na jamii, msaada wa fedha, mafunzo, kampeni.*
3. Elezea huduma ya kuwaunganisha tena na jamii inayotolewa kwa wagonjwa wa fistula katika kituo hiki? *Peleleza upatikanaji na utoshelevu wa huduma zilizotajwa*
4. Ni huduma gani nyingine muhimu za kuwaunganisha wagonjwa wa fistula katika jamii zinazohitajika? *chunguza njia bora kwa ajili ya kuwaunganisha kama vile ushauri nasaha, matibabu / upasuaji, ukarabati, kuwaunganisha na jamii, msaada wa fedha, mafunzo, kampeni.*
5. Kwa maoni yako, ni kiwango gani ambacho wanawake ambao wanakabiliwa na hali hii wanjiunganisha tena katika jamii baada ya upasuaji? *chunguza zaidi kufafanua jibu, changamoto wanazokabiliwa na mambo yanayowawezesha kuwaunganisha.*

ASANTE

Appendix 7: Informed consent form (Family & health care providers)

HEALTH SEEKING BEHAVIOUR AND REINTEGRATION OF PATIENTS WITH OBSTETRIC FISTULA IN KENYA

Informed Consent Form (Family Members and Key Informants)

Principal Investigator: Anne M. Khisa

Supervisors: 1 Professor Grace Omoni

2. Professor Isaac K. Nyamongo

Sponsors Name: Consortium for Advanced Training and Research in Africa (CARTA)

Part I: Consent Information Sheet

Introduction

Good morning/ afternoon. My name is Anne Khisa. I am a student at the University of Nairobi and as part of my studies I am carrying out a study on obstetric fistula. I would appreciate if you agree to participate in this study. Before you decide on whether to join the study or not, you will be provided with information regarding the study, a chance to ask questions and availed with a copy of this information sheet to keep.

Why is this study being done? The study seeks to investigate the kind of help that women seek while suffering from obstetric fistula and how they settle back into their communities after surgery. You are being asked to join the study in your capacity as **family member** or an individual whose work involves direct care of women who suffer from obstetric fistula. The study is being conducted in three hospitals in Kenya.

Are there any risks? If you join the study you may feel anxious when answering questions from the study. There is no physical risk anticipated by participating in this study.

What benefit can you expect? While the facts we obtain from study might not help you directly, by participating, you provide useful information that will help treatment programs to provide care to patients with obstetric fistula in a better way.

Will you be paid to be in the study? The study does not offer any monetary or material benefit to the participants.

You may refuse to be in the study. You are free to decline joining the study or to withdraw from this study at any point, and in such a case no penalty or disfavour will be shown towards you.

Confidentiality The information you give will be treated confidentially and your true identity shall not be revealed.

Withdrawal from the study: You are free to withdraw from the study at any stage and are not bound to provide any reasons. During interviews, it is your right to stop the interview at any point in time or decline to answer some of the questions

Do you have any questions? Please feel free to ask any question you may have concerning the study.

Contact Information

Should you need to clarify your rights as a study participant please contact Professor Guantai, Chairman, KNH/UON Research Ethics committee, Tel 020 726300 P.O. Box 20723-00202 Nairobi, Email: knhuonerc@gmail.com

Or contact Dr Grace Omoni, Director School of Nursing, University of Nairobi, on Tel. 0202711250 P.O Box 19676 – 00202 Nairobi, Email: omonigrace@hotmail.com

Should you need any help or information regarding the study contact the researcher, Anne Khisa, Tel. 0724 348 661, P.O Box 14670-00100 Nairobi, Email: annekhisa@gmail.com

Part II: Certificate of Consent

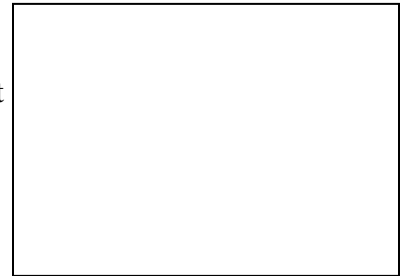
Research participant

I have been invited to participate in the study on obstetric fistula in Kenya. The foregoing information has been read to me. I have had the opportunity to ask questions about it and have been answered to my satisfaction. I hereby declare that I have voluntarily opted to participate in the study.

Signature: _____ **OR** Thumbprint

Date: _____

Time: _____



Researcher

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

1. The information given shall be handled in a confidential manner
2. Their true identity will not be revealed
3. Their freedom to withdraw from the study will be guaranteed and no disfavour will be shown to them in case they decide to withdraw.

I confirm that the participant has had opportunity to ask questions about the study and have answered him/her correctly. The participant has freely and voluntarily accepted to participate in the study and has not been coerced into giving consent. The participant has been provided with a copy of this informed consent form.

Interviewers Name: _____ Signature: _____ Date: _____

Time: _____ Participant Code No. _____

Site No _____

TABIA YA KUTAFUTA AFYA NA KUAUNGANISHA NA JAMII WAGONJWA WANAOGUA FISTULA ITOKANAYO NA UZAZI NCHINI KENYA

Fomu Ya Ridhaa Ya Wanafamilia Na Wahojiwa Muhimu

Mkuu wa uchunguzi: Anne M. Khisa

Wasimamizi: 1 Professor Grace Omoni

2 Professor Isaac K. Nyamongo

Wadhamini: Consortium for Advanced Training and Research in Africa (CARTA) *muungano wa mafunzo ya juu na utafiti katika Afrika*

Sehemu ya I: Karatasi ya Maelezo ya Idhini

Utangulizi

Habari za asubuhi / mchana. Jina langu ni Anne Khisa. Mimi ni mwanafunzi katika Chuo Kikuu cha Nairobi na kama sehemu ya masomo yangu mimi ninafanya utafiti juu ya fistula ya uzazi. Kabla ya kuamua iwapo kujiunga na utafiti au la, wewe utatapewa taarifa kuhusu utafiti huo, nafasi ya kuuliza maswali na utapewa nakala ya karatasi hii habari ya kuhifadhi.

Kwa nini utafiti huu unafanywa? Utafiti huu unalenga kuchunguza aina ya msaada wanawake hutafuta wakati wakiwa wagonjwa wa fistula itokanayo na uzazi, na jinsi wanavyorudi kukaa katika jamii zao baada ya upasuaji. Unaombwa kujiunga na utafiti huu kama **mwanafamilia** au mtu anyemhudumia mgonjwa ambaye amefanyiwa upasuaji kwa ajili ya fistula ya uzazi.

Je kuna hatari? Unapojiunga na utafiti huu, unaweza kuhisi aibu, wasiwasi wakati ukijibu maswali ya utafiti huu. Haitarajiwi kuwa kuna hatari zozote za kimwili zinatokana na kushiriki katika utafiti huu.

Ni faida gani unaweza kutarajia? Habari tutakazopata kwa utafiti huu haziwezi kukufaidi moja kwa moj. Hata hivyo, taarifa hizi muhimu zitasaidia programu za matibabu kutoa huduma kwa wagonjwa wa fistula ya uzazi kwa njia bora zaidi.

Je utalipwa kwa kushiriki katika utafiti? Utafiti huu hautoi faida yoyote ya fedha au vifaa vyovyote kwa washiriki.

Unaweza kukataa kushiriki utafiti huu. Una uhuru kukataa kujiunga na utafiti huu au kuondoka kutoka utafiti huu wakati wowote, na katika hali kama hiyo hakuna adhabu au karaha itaonyeshwa dhidi yako. Kumbuka ya kwamba una uhuru kuyaacha mahojiano haya wakati wowote na haitakulazimu kutoa sababu zako za kuondoka. unawezapia kukataa kuyajibu baadhi ya maswali wakati wa mahojiano.

Usiri. Habari utakayotoa itashughulikiwa kwa siri na utambulisho wako wa kweli hautafichuliwa.

Je una maswali yoyote? Tafadhali jisikie huru kuuliza swali lolote unaweza kuwa nalo juu ya utafiti kabla ya kunipa idhini yako.

Maelezo ya mawasiliano. Je, unahitaji maelezo kuhusu haki yako kama mshiriki katika utafiti huu? Tafadhali wasiliana na Profesa Guantai, Mwenyekiti wa Kamati ya Maadili ya Utafiti KNH/ UON Nambari ya simu: 020 726300 ext. 44102, Sanduku la posta: 20723-00202 Nairobi, Barua pepe: knhuonerc@gmail.com

Unaweza kuwasiliana na Dr Grace Omoni, mkurugenzi wa shule ya uuguzi, Chuo kikuu cha Nairobi, nambari ya simu 0202711250, Barua pepe: omonigrace@hotmail.com, sanduku la posta 19676 – 00202 Nairobi,

Je, unahitaji msaada au habari kuhusu utafiti huu? Tafadhali wasiliana nami mtafiti Anne Khisa Nambari ya simu: 0724 348 661, Sanduku la Posta: 14670-00100 Nairobi, Barua pepe: annekhisa@gmail.com

Sehemu ya II: Hati ya Idhini

Nimealikwa kushiriki katika utafiti juu ya fistula itokanayo na uzazi nchini Kenya. Nimesomewa habari inayotangulia hapo juu na nimekuwa na nafasi ya kuuliza maswali kuhusu utafiti huu. Nimeridhika na jinsi maswali yangu yamejibiwa. Mimi ninatangaza ya kwamba nimeamua kujitolea kwa hiari bila kushurutishwa ili kushiriki katika utafiti huu.

Mshiriki Wa Utafiti

Sahihi: _____ Au Alama ya Kidole Gumba

Tarehe: _____

Wakati: _____



Mtafiti

Mimi nimemsomea mshiriki uwezo karatasi hii ya habari kwa usahihi, na kwa kadri ya uwezo wangu nimehakikisha kuwa mshiriki anaelewa kuwa yafuatayo yatafanyika: 1)Maelezo yatakayotolewa yatashughulikiwa kwa njia ya siri Utambulisho wake wa kweli hautafichuliwa

2) Uhuru wake wa kujiondoa kutoka utafiti utahakikishwa na hakuna adhabu au karaha itakayo onyeshwa dhidi yake.

3) Ninathibitisha kuwa mshiriki amepewa nafasi ya kuuliza maswali juu ya utafiti huu na kuwa nimemjibu kwa usahihi. Mshiriki amekubali kushiriki katika utafiti kwa hiari yake na hajashurutishwa vyovyote vile ili kutoa idhini. Mshiriki amepewa nakala ya fomu hii ya ridhaa.

Jina la Mhoji: _____

Sahihi: _____ Tarehe: _____ Wakati: _____

Nambari ya kificho ya Mhojiwa _____

Nambari ya kificho ya Stesheni _____

Appendix 8: Study participant contacts index for follow-up

Patient Name	Code Number	Phone no	District	Location	Sub-location/ Village	Spouse contact	Telephone Number	Community Health Worker/ TBA (Name)	CHW/ TBA Contact

Appendix 9: Ethical Clearance



UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
P O BOX 19676 Code 00202
Telegrams: varsity
(254-020) 2726300 Ext 44355
Ref: KNH-ERC/A/68

KNH/UON-ERC
Email: uonknh_erc@uonbi.ac.ke
Website: www.uonbi.ac.ke
Link: www.uonbi.ac.ke/activities/KNHUoN



KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi
4th April 2013

Anne Majuma Khisa
P O BOX 14670-00100
NAIROBI

Dear Anne

RESEARCH PROPOSAL: HEALTH SEEKING BEHAVIOR AND REINTEGRATION OF PATIENTS WITH OBSTETRIC FISTULA IN KENYA (P618/11/2012)

This is to inform you that the KNH/UoN-Ethics & Research Committee (KNH/UoN-ERC) has reviewed and **approved** your above revised proposal. The approval periods are 4th April 2013 to 3rd April 2014.

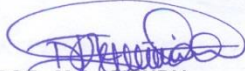
This approval is subject to compliance with the following requirements:

- a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- b) All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH/UoN ERC before implementation.
- c) Death and life threatening problems and severe adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH/UoN ERC within 72 hours of notification.
- d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH/UoN ERC within 72 hours.
- e) Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal.*)
- f) Clearance for export of biological specimens must be obtained from KNH/UoN-Ethics & Research Committee for each batch of shipment.
- g) Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.

Protect to Discover

For more details consult the KNH/UoN ERC website www.uonbi.ac.ke/activities/KNHUoN

Yours sincerely



PROF. M. L. CHINDIA
SECRETARY, KNH/UON-ERC

c.c. Prof. A.N. Guantai, Chairperson, KNH/UoN-ERC
The Deputy Director CS, KNH
The Principal, College of Health Sciences, UoN
The Director, School of Nursing Sciences, UoN
Supervisors: Dr. Grace Omoni, Prof. Isaac Nyamongo

Protect to Discover

Appendix 10: Codebook for the study

Code Name (Nodes)	Child Nodes	Description/Properties
Pathway to treatment	Narration of the various channels the participant took in seeking healing of the vaginal fistula; includes formal and informal networks; hospitals, traditional medicine; chain of referral	
	Hospital	The hospital, clinic or other health facility that provided care during fistula illness
	Payment	
	Referral during VVF Treatment	
	Seeking traditional medicine	
	Reason for seeking treatment	
	Disclosing illness	The process and actors involved in a participants disclosure of illness; health care providers, and kin (family, friends, neighbours; reasons for the disclosure; how others discovered the participant's illness
Living with fistula	The experiences of the participant during illness with obstetric fistula; their perception of life with the illness; the physical symptoms; feelings associated with the illness; <i>invivo</i> codes such as suffering; psychological contexts as contemplating suicide; participating in social activities lives; sexual lives; coping with illness	
	Lacking money	
	Suffering	
	Fear	
	Having sexual relations	
	Psychological thoughts	
	Hygiene	
	Participating in funerals, social	
	Children coping	The manner in which the children of a woman living with fistula are affected and cope with her illness.
	I stayed with my problem	An <i>invivo</i> code that arising often times when participants described the illness
	Hospital stay	length of time participant stayed in hospital because of the obstetric fistula illness
	Coping	How the participant is morally, or psychologically encouraged to get through life with the

		illness
	Social isolation	
Marriage and childbirth	Marriage and childbirth during fistula illness; participants who delivered a baby during the obstetric fistula illness; insights and perceptions on having a child when living with the condition.	
	Getting a child	
	Marrying	
Religious beliefs		
Health care provider response to vvf symptoms	How health workers responded to the participants illness; includes ability to recognise and diagnose vaginal fistula; level of understanding the illness; explanations offered to the participant; referral	
Recognition of symptoms	the participant's description of symptoms of vaginal fistula	
	Understanding nature of illness	
	Understanding cause of illness	
	Inability to control urine	
	Realising faecal incontinence	
	Linking women to care	
Childbirth	Participant's description of events of the labour and childbirth (during the pregnancy that caused the illness) or prior to the illness. Could include being referred during labour; place the baby was delivered; persons who assisted the woman to deliver the baby; traditional birth attendants; outcome of the baby (alive or died/ stillbirth).	
	Child died	
	Labour and delivered from home	
	Delivering in hospital	
	Illness in pregnancy	
	Managing labour	
	Being referred in labour	
	Traditional birth attendant	
	Cultural practices	
	Cause of illness	

Social support systems	The support received by patient during illness from family, spouse, friends and other people comprising her social network	
	Being supported by spouse	
	Being supported by natal family	
	Support to vvf patient by friend	
	Involving other family members	
	Separated with my husband	
	School	
Health seeking behaviour	The places and people the participant contacted to seek treatment for vaginal fistula illness. Includes referral points, assessment of the kind of help they received at various points and reasons why they chose to seek help at these points/ persons. The mode of access including advertisements on radio and use of mobile phones.	
	Assessing help received	
	Heard Radio advertisement	
	Using mobile phones to access vf care	
	Treating VVF	Participant description of how obstetric fistula was treated. Includes surgery undergone, advice given, medications received, follow-up visits or phone calls.
	Describing treatment	
	Multiple surgeries	participant had undergone more than one surgery to treat obstetric fistula
	Follow up	a participant was followed up by members of the health provision team to check on progress or for further treatment; phone calls, visits by social worker or linking organisation
Reintegration	Social interactions	participants social networks and interactions post fistula surgery
	Physical health	how participants perceive thier physical health since being discharged from hospital
	Gender roles	How women perform the roles expected of them as women in the community, especially in relation to their physical condition after surgery and the discharge instruction of avoiding manual work.
	Support by family	Participant described the support received from family members that helped the participant settle back to normal life
	Abstinance and couple	Participants description of how they adhered to the discharge instruction of 6 months

	marital challenges	abstinence post fistula surgery
	Divorce and separation	Women who experience periods of separation from the spouse, or even divorce as a result of fistula illness and adhering to treatment instructions like abstinence.
	Dependence for sustenance	Emergent theme in participant's narratives, of women having to depend on kin and well-wishers for their basic needs after surgery.
	Expectation surgery outcome	What the participant expected going into surgical treatment
	Family coping	How does the fistula illness affect the family, and how do they deal with it?
	Suicide and psychological health	Participants' psychological and emotional thoughts describing suicidal, thoughts, agony ad distress. also includes describes the psychological support needed by women after surgery
	Fertility concerns	The reproductive ambitions of women and their spouses following fistula surgery, bearing/ begetting children,
	Skill training	Participants who are being trained in any type of skill like, tailoring or business or engaged in after surgery.
	Reintegration status	A participant deemed as fully reintegrated back in society after fistula surgery, this could be classified as partially reintegrated and not reintegrated
	Community support	how community members have supported the participant after discharge from hospital after VVF surgery

Appendix 11: Review of Papers on Obstetric Fistula

The objective of this literature review was to obtain information on

1. Prevalence of fistula in Kenya and globally
2. The experience of living with obstetric fistula and consequences of fistula illness
3. Health seeking behaviour of patients with obstetric fistula
4. Reintegration of patients after obstetric fistula surgery

Author/ year/Country	Title of Paper & Reference	Design, Method & Sample	Objectives	Key Findings	Critique
African Medical And Research Foundation (AMREF) 2011. Kenya	Clinical outreach programme annual summary report 2009/2010. AMREF.	Summative evaluation report	To document the project outcomes versus set objectives	AMREF partnered with international funders and government teaching and referral hospitals and fistula surgeons to offer free fistula repair surgeries 1200 surgeries conducted in 2010 Note that women spend decades before surgery	Documentation is important for mapping the progress of fistula surgery in the country. Gives estimate of the fistula surgery capacity in the country against existing backlog The report does not comment on concepts of health seeking behaviour nor reintegration
Ahmed, S. & Holtz, S. A. 2007. Developing countries	Social and economic consequences of obstetric fistula: Life changed forever? <i>International Journal of Gynecology and Obstetrics</i> , 99, S10- S15.	Meta- analysis A systematic review of literature between 1985 – 2005 in developing countries	To summarize the social, economic, mental and psychologi cal consequenc es of fistula To present meta-	High foetal and perinatal death rates associated with obstetric fistula Fistula and loss of baby lower women's social status and lead to divorce Report a wide range of social and psychological consequence of fistula illness Social isolation, divorce,	An extensive review of existing literature on OF Strong evidence collated from different studies. Meta-analysis focus only on marriage and child loss; excluding others such as infertility and sexual health though these are mentioned in the literature review.

			<p>analysis for 2 major consequences of obstetric fistula on women's lives - marriage and perinatal child loss</p>	<p>dependence on relatives, mourning the lost baby,</p> <p>Difficulty in maintaining sexual relationships, decreased libido and husbands lost sexual pleasure with their wives</p> <p>Depression, low self-esteem, stress, anxiety,</p> <p>Obstetric injury complex – amenorrhea, foot drop, excoriation of private parts, infection, infertility, renal calculi, Malnutrition is common Surgery improves physical and mental health of affected women Additional social support and counselling is required for reintegration</p> <p>Conclude the need to treat women with fistula both on humanitarian and social justice and addressing women's reproductive rights basis</p>	<p>Report few studies on rehabilitation and suggest a broad social and lifecycle approach based on only 1 study Does not comment on health seeking behaviour of fistula patients</p> <p>Does not comment on each paper reviewed, its limitations especially methodology used</p>
<p>Yeakey, M. P., Chipeta, E., Tauro, F. & Tsui, A. O. 2009. Malawi</p>	<p>The lived experience of Malawian women with obstetric fistula. <i>Culture, Health & Sexuality</i>, 11, 499-513.</p>	<p>Phenomenology</p> <p>N=45 women N=30 family</p>	<p>To describe the lived experience of women with obstetric fistula</p>	<p>Triangulation of data sources is important in validating data – patients and family.</p> <p>Participants had had previous treatment, formal and traditional, but were unsuccessful and still</p>	<p>This paper is vital in shedding light on what becomes of women's lives during fistula illness. The authors discussion of varied positive and negative findings contribute to further debate on fistula, removing the common negative narrative and</p>

		<p>members</p> <p>Hospital records and Respondent driven sampling (snowball?)</p> <p>Key informants</p>		<p>living with fistula; Discusses findings within the lens of the social construction of women gender of the Yao community – focusing on marriage, intimate relationships and childbearing</p> <p>Reports high levels of divorce and separation as well as women marrying again during fistula illness.</p> <p>Due to societal expectations of women to bear children, fistula survivors who had children were more likely to stay on with the husband and even though he took up a new wife, she remained.</p> <p>Women’s failure to fulfil gender roles leads to their feeling sadness, hopelessness, powerlessness, desperation, depression and suicidal thoughts.</p> <p>Authors separate the intrapersonal effect of fistula poor mental health;</p> <p>From the interpersonal relationships e.g. stigma and divorce, noting the variety of outcomes on women</p>	<p>pointing to possible spousal support to women in certain circumstances.</p> <p>The use of the social construct of gender in analysing data helps readers to understand the plight of women intra and interpersonal whilst taking into account the macro-sphere- social context within which women develop fistula.</p> <p>The use of phenomenology allows emic perspectives; and the use of key informants allows the etic – hence a complete picture of women’s experiences.</p> <p>Although authors report that the women had sought treatment – health seeking behaviour – they do not further comment on or expound on the health seeking behaviour of women with fistula.</p> <p>The reintegration of women with fistula is naturally not commented on here since they have not obtained treatment. But perhaps the attempts of women to live normal sexual and married lives and begetting children is a possible indicator to what women desire - to be normal again as expected of them in</p>
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					society.
Gwyneth, L. & Bernis, L. D. 2006.	Obstetric Fistula: Guiding Principles for Clinical Management and Programme development. Geneva, World Health Organisation.	Review of existing literature and evidence on fistula care	Developed guidelines for clinical and program global use	<p>A contextual understanding of the plight of women with fistula</p> <p>Report that women may be unaware of the treatment for fistula; the health system may also lack dedicated hospitals for fistula care and few or no expert surgeons for fistula reparative surgery. Clinical care guidelines – surgery, nursing, physiotherapy, principles of reintegration and rehabilitation</p> <p>Reintegration that includes emotional, psychological and economic support.</p> <p>Counselling on causes of OF, good obstetric care and FP and offering women opportunity to talk about their experience and interact with other fistula patients.</p> <p>Family and community roles in reintegration.</p> <p>Suggest community education, advocacy and research to map communities of origin for patients.</p>	<p>The guiding principles are a valuable document, drawing from what is known about fistula illness, to guide care.</p> <p>However, the guidelines are on the macro level and countries and regions may need more context specific information to address specific needs of fistula patients.</p> <p>The guidelines do not comment on nor highlight the health seeking behaviour of fistula patients.</p>
Mabeya, H. 2004. Kenya	Characteristics of women admitted with obstetric fistula in the rural hospitals of West Pokot, Kenya.	Descriptive study over 5 year period N=66	To determine prevalence rate and Characteristics of	<ul style="list-style-type: none"> ▪ Prevalence of obstetric fistula was 1 per 1000 women ▪ Characteristics of patients <p>Mean age of obstetric fistula patients 22.8 years (median 20)</p>	<p>The study is valuable as is the first prevalence study conducted in Kenya giving an estimate burden of the disease.</p> <p>The authors acknowledge the methodological limitations of the</p>

	Geneva Foundation for Medical Education and Research.		women with obstetric fistula in rural hospitals in West Pokot, Kenya To determine birth outcomes for fistula patients	Age at fistula mean 20.5 (median 19, range 14-38) 55% were primi-gravida; 55% with formal education; 56% married at admission; 80% had FMG infibulation <ul style="list-style-type: none"> ▪ Birth outcomes –majority 75% had prolonged labour; 79% delivered in Hospitals and 50% CS and 20 assisted vaginal delivery; 67.7% stillbirths ▪ HSB, over 46% reported to hospital after 1 year of leakage; 86% success rate (closure) at first surgery 	hospital based study to estimate population based parameters as prevalence.
International Federation for Gynecology and Obstetrics (FIGO) 2006.	Ethical guidelines on obstetric fistula. <i>International Journal of Gynaecology and Obstetrics</i> , 94, 174-175.	Review Committee Report	To provide material for debate around ethical aspects of	The authors note that obstetric fistula is distressing to women’s health and often results in loss of the baby They note that obstetric fistula has been eradicated in the developed countries through improved obstetric care, and is preventable. While some women may be unaware of the available surgical treatment for fistula, others may not afford it. Fistula patients need surgery and also social and psychological support into the community FIGO makes 8 recommendations on access to adequate healthcare to	An important summary of the core issues surrounding fistula at the time that are still applicable today. However, the committee addresses the global perspective to fistula illness as reported from different literature but does not address specific contextual issues at the micro level. For instance, while some communities practising FGM do experience obstetric fistula, our study in Kenya has revealed VVF even in women who have not undergone FGM. It could be those who cut and don’t are sharing certain common contributing

				women in pregnancy; empowerment of women; eradication of FGM; building capacity for fistula repair with south north and south-south collaborations; inclusion in medical school curriculum for prevention and treatment; health education campaigns and development of national strategy to eliminate fistula.	factors to formation of obstetric fistula, for instance lack of adequate healthcare during delivery. The recognition of surgery, social support and reintegration as an ethical issue underscores the importance of the recovery period after surgery
Mselle, L. T., Kohi, T. W., Mvungi, A., Evjen-Olsen, B. & Moland, K. M. 2011a. Tanzania	Waiting for attention and care: birthing accounts of women in rural Tanzania who developed obstetric fistula as an outcome of labour. <i>BMC Pregnancy and Childbirth</i> , 11, 75.	Concurrent qualitative dominant mixed methods design N=16 Qual N=151 Quant	To explore experiences of women with fistula To assess barriers to accessing quality care in labour and delivery	Use a theoretical framework of AAAQ (Available, accessible, Affordable, Quality) and the Three delays model Women in index labour to VVF experience delays in decision to seeking care at the hospital – (seeking adequate care). in addition to lack of money and long distance to health facilities- (identifying a health facility to go to) At facilities, women delay in obtaining emergency obstetric care due to unskilled care (TBAs) operating in health centres, and few nurse midwives available – (receiving inadequate care.) This last poor quality of care undermines women’s future decision to seek hospital births; or	Authors focus on the events surrounding childbirth is a strength as it offers insight on how the occurrence of obstetric fistula may be prevented through elimination of the three delays and improved quality of care offered. Use of mixed methods design is strong in triangulating findings through different source methods. Data from quantitative arm are however not adequately interpreted and leaves the reader to infer meaning of the tables provided Though authors do not comment on the experience of living with fistula illness, health seeking or reintegration concepts, this paper is useful in shedding light on how obstetric fistula occurs and thus

				go to health facilities further away hence further second delay	relevant to my literature review.
Mselle, L. T., Moland, K. M., Evjen-Olsen, B., Mvungi, A. & Kohi, T. W. 2011b. Tanzania	“I am nothing”: Experiences of loss among women suffering from severe birth injuries in Tanzania <i>BMC Women’s Health</i> , 11: 75.	Concurrent qualitative dominant mixed methods design N=16 Qual N=151 quant	To explore the physical, cultural and psychological dimensions of living with fistula To demonstrate how women’s experiences shape their identities	Used concepts of <ul style="list-style-type: none"> ▪ social and personal identity by Richard Jenkins ▪ disability by World Health Organisation 1976 ▪ discrimination by Erving Goffman Report fistula patients’ loss of <ul style="list-style-type: none"> ▪ body control, ▪ social role of woman and wife ▪ integration in social life ▪ dignity and self- worth Associated living with fistula with multiple physical, emotional and social losses fistula occurrence is a result in inequity to be addressed through social and economic development, and obstetric care recommend -fistula patients educational programs for women’s economic and social empowerment Counselling to family of affected women to give medical and social support; and society on issues associated with fistula occurrence and its management and women’s	The three concepts of identity, disability and discrimination as used in this study are intertwined and the authors do not offer sufficient discussion of how each concept by itself applied to the patients with fistula; they also do not offer a description of how each of these concepts varied or were similar to those described by original postulators of the concept. For instance, disability and identity are introduced but not expounded in discussion, although authors refer to identity in making their concluding recommendations. Stigma and discrimination however are adequately discussed. This paper is valuable to my review as it highlights the experience of living with fistula and the effect this experience has on their identities. Although the authors do not make direct reference to women’s health seeking behaviour during fistula illness, the authors touch on self - esteem. A core issue central to individuals’ perception of

				reproductive potential after surgery to improve women's perceived worth and social identity after fistula surgery.	themselves, their worth and the ensuing/ pursuant help seeking in times of crisis.
<p>Khisa, W., Stephen, M., W., M. J., Zahida, Q., Jessica, B. & Pavithra, V. 2011.</p> <p>Kenya</p>	<p>Depression among women with obstetric fistula in Kenya.</p> <p><i>International Journal of Gynecology and Obstetrics</i>, 115, 31-33.</p>	<p>Cross-sectional study</p> <p>N=70</p>	<p>To establish prevalence of depression and associated factors</p>	<p>17.1% had suicidal ideation and depression was present in 72.9% of fistula patients</p> <p>Depression was associated with being older than 20 years, having no social support, being unemployed and living with fistula for more than 3 months.</p> <p>Childlessness and infertility were not associated with depression.</p> <p>Authors recommended holistic approach to care to include mental healthcare and family support</p>	<p>The authors focus on one aspect of mental health i.e. depression, mental illness and suicidal ideation whilst in itself welcome; it was excluding other measures such as self-esteem etc.</p> <p>Most importantly, there is no description of the type of counselling availed to patients if any and the extent to which this would have impacted the patients; a pre-test and post-test after counselling and psychotherapy would be more valuable measure of depression and its remedies.</p> <p>Methodologically, self-report questionnaires are limited in reporting the patients' full experience and the meaning they make out of the phenomena.</p>
<p>Khisa, A. M. & Nyamongo, I. K. 2012.</p> <p>Kenya</p>	<p>Still living with fistula: an exploratory study of the experience of women with obstetric fistula following corrective surgery in West</p>	<p>Exploratory qualitative study</p> <p>N=8</p>	<p>To document challenges faced by women following corrective surgery</p>	<p>Interviewed women who had both healed or not healed from fistula in a cultural group that conducts FGM and marries off girls in teenage</p> <p>Though others were healed, all women reported continuing</p>	<p>The small sample though suitable for exploratory study, is context specific and narrow focus may not be applicable to the broader fistula patients populations in Kenya. for instance, communities that have few or no early marriages, communities that do not practice</p>

	<p>Pokot, Kenya.</p> <p><i>Reproductive Health Matters, 20, 59-66.</i></p>		<p>Within the broader context of women's health</p>	<p>problems after fistula surgery similar to before surgery – isolation, shame and stigma, separation and divorce, reduced sense of worth and psychological trauma and unemployment. Those with unsuccessful surgery had more dire outcomes than the ones who were healed.</p> <p>The authors recommended that key actors in reintegration are husbands, family and community ; and public health education and reintegration programs to target broader outcomes beyond corrective surgery</p>	<p>FGM and other harmful cultural practices leading to obstructed labour were not included. Further, educated women or older women were not included and these may have provided avenues for further differential analysis on the outcomes of surgery.</p> <p>Triangulation of data sources is a methodological strength of this study</p> <p>The authors, though reporting women's disappointment that they cannot get children nor marry again, they do not further explore this further. Other studies have since shown that pregnancy is possible during and after fistula illness and infertility s a source of stress to women. These possibly are what made the women in this cultural context not feel as though fulfilling their gender roles.</p>
<p>Kenya National Bureau Of Statistics (KNBS), Ministry Of Health (MOH), National Aids Control Council</p>	<p>Kenya Demographic and Health Survey 2014 Key Indicators, Nairobi, Government of Kenya.</p>	<p>Cross sectional study conducted every 5 years</p>	<p>Survey conducted every 5 years to establish key health indicators in Kenya</p>	<p>Prevalence of vaginal fistula is at 1% of women in Kenya</p>	<p>A significant prevalence study to fill the knowledge gap on the magnitude of vaginal fistula problem in Kenya.</p> <p>There seems more women living with fistula than previously estimated by a facility based study</p>

<p>(NACC), Kenya Medical Research Institute (KEMRI) & National Council For Population And Development (NCPD) 2015.</p>					<p>by Mabeya (2004)</p>
<p>Mcfadden, E., Taleski, S. K., Bocking, A., Spitzer, R. F. & Mabeya, H. 2011. Kenya</p>	<p>Retrospective review of predisposing factors and surgical outcomes in obstetric fistula patients at a single teaching hospital in western Kenya. <i>Journal of Obstetrics and Gynaecology Canada</i>, 33, 30-35.</p>	<p>Descriptive study? Hospital records review N=86</p>	<p>To examine success rates and complications of OF repair in association with sociocultural and socioeconomic determinants of health</p>	<p>Mean age at repair 25.5 years 25% had experienced incontinence for 1-5 years and 19% for longer than 5 years. Authors report delivery as CS for 52% of women, 18% for instrument vaginal delivery; mean duration of labour 56 hours 56% stillbirths and 14% neonatal deaths. 92% caused by obstructed labour and 8% by iatrogenic injury in CS, injury in late CS and ruptured uterus. Difficult to repair fistulas and size of fistula were related to incontinence post repair. Despite 95% closure rates, 45% of women experienced urinary incontinence prior to discharge postoperatively. Women had their surgeries waived</p>	<p>The authors attempt to categorise the time spent living with fistula is valuable to understand the period before surgery. The characteristics of fistula patients demonstrated here are similar to other studies, and my own study findings The authors aim to associate sociocultural and economic factors to success rates of fistula was not achieved since in the end only data showing associations of fistula size and surgical outcome.</p>

<p>Khisa, A. M. & Nyamongo, I. K. 2011.</p> <p>Kenya</p>	<p>What factors contribute to obstetric fistulae formation in rural Kenya?</p> <p><i>African Journal of Midwifery and Women's Health</i>, 5, 95-100.</p>	<p>Exploratory qualitative study</p> <p>N=8 healthcare providers</p>	<p>To explore the perspective of healthcare providers on the contributing factors to formation of fistula</p>	<p>The factors that contribute to fistula formation are - FGM and early forced marriage; unskilled births attendants and associated birth rituals; infrastructural challenges and lack of women's empowerment; demonstrating interplay between sociocultural, structural and economic forces to formation of fistula.</p> <p>Authors recommend community level initiatives to improve women's health in rural areas.</p>	<p>The small sample though suitable for exploratory study, is context specific and narrow focus may not be applicable to the broader fistula patient's populations in Kenya.</p> <p>In-depth interviews give explanation to what opinions are being expressed by key informants.</p> <p>Often, healthcare providers give an etic opinion on why obstetric fistula conditions occur. Although in this case the factors mentioned by the health care providers mimic those reported by other studies, getting the women's narratives around the context in which fistula occurs would have been more enriching emic perspective.</p> <p>However, the evidence presented is invaluable in understanding the community level factors contribute to fistula in one rural community in Kenya</p>
<p>Omari, J., Wakasiaka, S., Khisa, W., Omoni, G. & Lavender, T. 2015.</p>	<p>Women and men's awareness of obstetric fistula in facilities in Kisii and Nyamira Counties, Kenya</p>	<p>Cross sectional study</p> <p>N=300</p>	<p>To establish men and women's awareness of fistula</p>	<p>Authors established that fistula information is lacking amongst community members attending child welfare, ANC and FP clinics; participants had limited understanding of what causes fistula, its prevention and</p>	<p>The study demonstrates a low level of awareness about fistula in two counties in Kenya. Its significant contribution to community based initiatives is invaluable in increasing awareness amongst community members, and practical</p>

Kenya	<i>African Journal of Midwifery and Women's Health, 9.</i>			<p>treatment.</p> <p>46.6% were aware of fistula with more men than women having heard of fistula. Educated participants were more likely to have heard of fistula than their uneducated counterparts. Authors' conclude that the awareness creation on radio and print media during fistula camps only is not sufficient to educate communities about fistula illness, calling for more innovative ways.</p>	suggestions.
<p>Khisa, A. M. 2015.</p> <p>Kenya</p>	<p>An Exploratory Study of Reintegration of Women Following Obstetric Fistula Surgery in West Pokot, Kenya. <i>SAGE Open, 5.</i></p>	<p>Exploratory qualitative study</p> <p>N=8</p>	<p>What factors influence the social reintegration of obstetric fistula survivors? How might we improve the effectiveness of the reintegration process for fistula survivors?</p>	<p>Women aged 17-30 years; four healed, other four still incontinent, six out of the eight women had no surviving children; two were still married. Interviews at 3-36 months after surgery</p> <p>Women cited as services to improve their reintegration as family support, counselling, income generating activities, skill training, successful surgery and government support.</p> <p>Author recommends addressing fertility concerns of fistula survivors and close monitored antenatal care during subsequent pregnancy and follow up for up to a year after surgery.</p> <p>Concludes that the reintegration</p>	<p>The small sample though suitable for exploratory study, is context specific and narrow focus may not be applicable to the broader fistula patient's populations in Kenya.</p> <p>The study offers patients opinion on what they need post surgery, and offers for the first time a</p> <p>The strength of this study was qualitative health research methods that allow the participant to give in-depth explanation and opinion; such methods show potential to better understand women's experiences and opinions about their health, illness and recovery.</p>

				needs of women may vary and are context specific Recommends a holistic approach to reintegration i.e. the biomedical, psychological, social and economic components	
Ministry Of Health Kenya & United Nations Fund For Population Activities 2004. Kenya	Needs assessment of obstetric fistula in Kenya: final report. Nairobi: Division of Reproductive Health.	Cross-sectional survey N= 4 districts in Kenya – Kwale, Mwingi, West Pokot, Homabay (10 facilities- 4 district hospitals, 1 subdistrict, 1 mission hospital, 2 health centres and 2 dispensaries And communities	Assessing 1 sociocultural factors contributing to fistula formation 2. Health seeking behaviour in relation to obstetric fistula 3. availability and utilization of essential obstetric services 4. to make recommendations on prevention and management of	<i>1 sociocultural factors contributing to fistula formation</i> – rugged terrain, expansive landscape, harmful cultural practices, poverty interact to form fistula; early marriage and early sexual debut; preference to deliver at the TBA and long distance to health facilities contribute to prolonged labour (cause of obstetric fistula) OF a neglected area of safe motherhood – at community level little understanding of the condition and its cause; Stigma exists in West Pokot but not the other districts Context within which fistula occurs goes beyond the health sector <i>2. Health seeking behaviour in relation to obstetric fistula</i> – limitations of skill, time and resources resulted in all districts treating less cases of fistula patients than diagnosed. Recommended capacity building	Mixed methods is a strong methodology that obtains evidence complimenting and explaining the meaning of data respectively. An important needs assessment that brings forth what is known on the fistula landscape in Kenya. the study did well to recognise current efforts ongoing in fistula care and pointed to the gap existing between existing fistula cases and the few repairs that are made; recommending capacity building for surgery and prevention; institutional preparedness and integrating fistula care within safe motherhood initiative activities. However, there is no mention of reintegration; also, the health seeking behaviour is focused only on reporting the women who report for treatment after seeing symptoms of leaking urine; there is no mention on the context surrounding women’s health seeking behaviour. This

		Mixed methods of data collection	obstetric fistula	for repair; lifesaving skills for nurse midwives to prevent fistula; addressing shortage of nurse midwives; Discussions at community revealed that women who leak urine after delivery are not immediately recognised as having fistula but may be advised to go to the hospital; other communities believed it is a bad luck incident, or she is not woman enough, or she was adulterous during pregnancy as some of the causes explained by community	information gap necessitates further research if fistula care is to be improved in the country.
Diallo, M. 2009. Guinea	Social immersion strategy for reintegration and empowerment of obstetric fistula survivors. <i>International Journal of Gynecology and Obstetrics</i> , 107, S156-S157.	Project description of a social immersion project in Guinea Abstract	To reintegrate fistula patients in previously stigmatising contexts	Project description of reintegration program for fistula patients that starts at the hospital into communities. Post op- physical and psychological therapy combined with Post op they live with a host family in the community as a social immersion strategy There is improved self-esteem, confidence and emotional health for the women The strategy also led to improved links between fistula repair facilities and the surrounding community	This is a second known study describing how social reintegration was obtained for women in a stigmatised context of fistula illness. Whilst context specific, it sheds light on the value of combining physical, psychological therapy with social support systems in the healing of fistula patients.
Arrowsmith, S.	Current practices in	Cross-	To identify	Common practices included	The sampling criterion excludes

<p>D., Ruminjo, J. & Landry, E. G. 2010.</p> <p>Africa and Asia</p>	<p>treatment of female genital fistula: a cross sectional study.</p> <p><i>BMC Pregnancy Childbirth</i>, 10, 73.</p>	<p>sectional study</p> <p>N=40 fistula surgeons in Africa and Asia</p> <p>Self-report questionnaire</p>	<p>practices in care[for fistula patients] that could lead to prospective and randomised controlled trial</p>	<p>limited bedrest until catheter is removed, nonsurgical treatment for post-surgical incontinence and prophylactic antibiotics. Other varying practices included duration of catheter use and surgical treatment for post-surgical incontinence.</p> <p>The authors based on the study findings recommended 8 randomised controlled trials in the cost, efficacy and safety of fistula treatment</p>	<p>other health care providers in clinical care of obstetric fistula, e.g. counsellors, social workers and nurses and their fistula care practices. The results therefore may exclude other views of these providers in post op care.</p> <p>The study is important in first recognising the widespread occurrence of residual urinary incontinence after fistula reparative surgery and suggests further research to improve of care of patients who present with such</p>
<p>Donnay, F. & Ramsey, K. 2006.</p>	<p>Eliminating Obstetric Fistula: Progress in partnership. .</p> <p><i>International Journal of Gynecology and Obstetrics</i>,94: 254 - 261.</p>	<p>Evaluation report of the Global Campaign to end Fistula</p>	<p>To describe the processes and strategies of the Global Campaign to End obstetric fistula</p>	<p>National and international partners are partnering to highlight the neglected condition- through obtaining commitment and resources for eliminating obstetric fistula; and pointing our gaps in maternal healthcare</p> <p>The campaign in 2001 bringing together UNFPA; Addis Ababa Fistula Hospital; Columbia University Averting Maternal Death and Disability Program; International Federation of gynaecology and Obstetrics; and World Health Organisation</p>	<p>An important report that documents the global efforts to asses needs and coordinated effort to eliminate obstetric fistula. The report documents efforts of the early 2000s international and helps situate obstetric fistula within the broader unmet needs of safe motherhood and women’s health.</p>

			<p>Rapid Needs assessment conducted in 9 African Countries [similar to or including Kenya and Tanzania] to collect data: - Most women living with fistula were poor, illiterate and young. Weak health systems, poverty and sociocultural factors hindered access to preventive obstetric services</p> <p>Lack of awareness among policy makers and public officials, sporadic treatments and few resources characterised available fistula treatment.</p> <p>The campaign led to formation of a body for coordinating efforts to eliminate obstetric fistula – the Obstetric Fistula Working Group that later became part of the Partnership for Maternal New born and Child Health; and formed the Guidelines for management of Obstetric fistula</p> <p>30 countries involved in the campaign in Africa, Asia, middle East; 20 countries performed needs assessments, 10 countries formulating national strategies on prevention, treatment and return of women to society.</p> <p>Campaign emphasizes the need for</p>	
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				social support services, health education and counselling to help treated women reintegrate into society. Mentions NGOs that have skill training and support for women after fistula surgery.	
Wall, L. L. 2012a.	A Framework for Analysing the Determinants of Obstetric Fistula Formation. <i>Studies in Family Planning</i> , 43, 255-272.	Review	To assess the problem of obstetric fistula using a framework originally designed to assess determinants of maternal mortality	Suggests a framework for prevention of fistula Three determinants of obstetric fistula are identified: Socioeconomic – women’s status, Intermediate – health, reproductive status, use of healthcare resources Acute clinical factors – Recommends sustained efforts that impact all three levels of determining factors.	This article is important in the prevention of obstetric fistula making relevant recommendations towards three levels of determining factors that offer chance for intervention. The authors innovatively use what is already existing frameworks on maternal health to suggest further strides in fistula prevention. The McCarthy and Maine framework that has been used in explaining obstructed labour, which in turn is a cause of obstructed labour is then most suitable for analysing determinants of fistula. However, walls framework has not been tested
Pope, Rachel Bangeser, Maggie Requejo, Jennifer Haus	Restoring dignity: Social reintegration after obstetric fistula repair in Ukerewe, Tanzania	Community control group Mixed -	Quality of life using Perceived Quality of Life(PQOL)	Reintegration issues explored - <ul style="list-style-type: none"> ▪ Social interactions ▪ Economic activities/ work ▪ Time ▪ Residual incontinence 	An important research building on the knowledge of reintegrating fistula patients. No theoretical framework is

<p>(2011) Tanzania</p>	<p><i>Global Public Health</i> 6(8):859-873</p>	<p>Quantitative & Qualitative - methods N=71 purposive, snowball</p>	<p>) and RNLI of fistula patients; compared to those treated for fistula; compared with those without fistula illness</p>	<p>There is improved quality of life after fistula surgery. Being able to work again in the fields was the most important factor in the reintegration process; however time required to recover impeded this activity. Family support helped women transition well back to their normal lives post op Women were afraid of physical or sexual activity as it would cause fistula recurrence; or experienced pain 48% reported persisting physical problems Women social roles of begetting children – only 3 had live births after fistula and the rest had a recurring fistula; those who had more than 3 children were not abandoned. Women who were financially depended before fistula also remained in this state or worsened after fistula surgery; upon spousal abandonment, the natal family supports the patients. At least a year (as time factor is significant in return to PRQOL) is</p>	<p>however reported for examining reintegration; two tools are adapted to measure reintegration – PRQOL and RNLI- although how they were modified to suit fistula patients is not extensively discussed.</p>
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				<p>needed for patients to return to PRQOL as before illness Stress urinary incontinence leads to lowest scores</p> <p>Awareness campaigns had reduced stigma, reduced time lived with fistula illness before surgery and better outcomes for patients Recommend post-surgical and follow-up care and training opportunities as reintegration mechanisms</p>	
Farmer, P. 2008.	<p>Challenging orthodoxies: the road ahead for health and human rights.</p> <p><i>Health and Human Rights</i>, 10.</p>	Editorial Commentary		<p>The author argues that the orthodox public health approach that formulates interventions that are ‘cost effective’ and ‘sustainable’ are noble in spirit but lack commitment to solve the public’s real problems of poverty and stop epidemics. He also notes that the conventional human rights focus on political and civil rights rather than food, health and education – the socioeconomic and health rights. Farmer argues that protecting the health of the poor should be the preoccupation of public health practitioners; to ‘challenge orthodoxies that defraud poor people of minimal requirements for healthy lives’</p>	<p>The author focusses on the context in which maternal morbidity and mortality and infectious diseases occur, often with fatal outcomes – the right to health. Written on the global scale and drawing from examples of Peru, Haiti, Malawi etc. the authors offer great insight based on experience working with the poor on why right to health is a social economic right, as import and as political and civil rights.</p> <p>The article is important in understanding in new light the issues surrounding maternal morbidity as obstetric fistula and other morbidities related to obstructed labour.</p>

			<p>Argues that the voiceless poor have a lot to say-and do tell clinicians and anthropologists- but human rights practitioners don't listen to them.</p> <p>That human rights and social justice are the staples of public health, giving examples of how this kind of thinking led to formation of PEPFAR, Global Fund Against AIDS, TB and Malaria.</p> <p>Argues that gender inequality and poverty are the cause of almost all deaths during childbirth – almost half million, majority of which are amongst poor women. Essential obstetric care provision, of personnel equipment and supplies should be the focus of human rights and public health experts.</p> <p>The author suggests that to understand poor maternal health, in Malawi for instance, there is need to do local analysis, but also scrutinise the political economy and powerful transnational institutions that determine policies in Malawi, postcolonial Africa and Latin America.</p> <p>Author calls for 'pragmatic and</p>	
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				expanded view of health and human rights’.	
United Nations 2010. Global	The millennium development goals report 2010. New York: UN.	Global health indicators		A global health report that focuses on key maternal and other health indicators	
Kabayambi, J., Baragaine, J. K., Matovu, J. K., Beyeza, J., Ekirapa, E. & Wanyenze, R. K. 2014. Uganda	Living with obstetric fistula. Perceived causes, challenges and coping strategies among women attending the fistula clinic at Mulago hospital, Uganda. <i>International journal of tropical disease and health</i> , 4.	Cross-sectional study N=30 Mixed methods – FGD, Semi-structured interviews, Key informants	To determine the perceived causes, challenges and coping mechanisms of women with obstetric fistula	Young women below 25 years (70%), primary education, lived with fistula for 2-9 years Perceived causes – big baby, injury by surgeon, prolonged labour. Challenges – [physical, emotional and socioeconomic] fistula had affected lives, loss of children; Family have to endure treatment costs, costs of basic items, and were stressed Coping – that is problem-based and emotion-based, i.e. hiding from public, strict hygiene [washing, bathing, use of lotion and sprays, frequent change of clothes], prayer, drinking lots of water and less food, use of polythene materials on top of clothes and ignoring people’s comments. Authors note that the social coping measures were ineffective and recommend awareness ,	Mixed methods research has the advantage of giving both the magnitude of phenomena being investigated and the experiences, meaning and perception of the phenomena by participants. By use of mixed methods, the authors comprehensively address the plight of women suffering obstetric fistula and how they cope with illness. This study focus on the experience during living with fistula helps us see the coping mechanisms women employ whilst living with fistula – albeit the authors note that the coping was dysfunctional in managing the illness. The way patients cope with illness determines how they seek treatment. For instance, avoidance of public and social interactions is common yet may hinder women from obtaining information about

				prevention and prompt treatment	treatment available. Thus dysfunction is introduced.
Wall, L. L. 2012b.	Obstetric Fistula Is a "Neglected Tropical Disease". <i>PLoS Neglected Tropical Diseases</i> , 6, e1769.	Editorial Commentary	To highlight how obstetric fistula is a neglected tropical disease	in the paper 'Obstetric Fistula Is a "Neglected Tropical Disease"' raises important issues that drives the academic discussion on obstetric fistula. They include prevalence of the condition, the problems that women living with fistula experience and the paradigm shift(s) necessary to address the problem. The author suggests a paradigmatic shift arguing that not only infectious pathogens in the tropics cause illness and suffering; there are other illness like fistula that affect the poor. A focus then should be on the neglected tropical <i>disorders</i> rather than the current focus on neglected tropical <i>diseases</i> , an approach which obscures the reality of other non-infectious illnesses in populations residing in the tropics. The author adopts a human rights approach stance to the problem of obstetric fistula, posing an argument that obstetric fistula is as a reproductive health illness that impacts negatively on the right of	By depicting the problems and suffering occasioned by the illness, the author generates sufficient factual evidence to back the call for resource mobilization towards preventing and treating the illness, albeit in a public health approach. The global approach to diseases in the tropics has tended to focus on infectious, pathogen driven diseases at the expense of other illness driven by the social determinant of health, or lack thereof. This article sought to put in perspective an argument that geography and pathophysiological disease categories oughtn't to obscure public health experts' attention to tackle significant reproductive health problems of these populations. The strength of this article lies in the human rights approach to women's reproductive health, while at the same time putting the epidemiology of the affected groups in perspective. In this light, the author clearly depicts the grim statistics of the illness compared to the little attention accorded the problem globally.

				<p>women to healthy reproductive lives.</p> <p>It is against the backdrop of reproductive health as human rights that the claim of obstetric fistula being a neglected tropical disorder can be made. By taking this stance, the author, claims authenticity and legitimate claim of the problem to the global public health debate, which often is obscured by big statistics and the ‘overall epidemic picture’ at the expense of other ‘meritous’ illnesses that affect the poor.</p>	<p>The author further highlights the gendered nature of the burden of disease that is obstetric fistula.</p> <p>These merits notwithstanding, the argument may have benefitted from a deeper gendered perspective to disease. For instance, I would argue that obstetric fistula is a neglected condition in many Asian and African communities firstly because it is a ‘women’s thing’. Typically, women’s sexual and reproductive health issues may not be taken seriously in patriarchal communities and are worsened by lack of women’s empowerment. The transformation in maternal morbidity statistics in the West may be attributed to improved healthcare infrastructure; which were in turn largely driven by women’s empowerment and the industrial revolution.</p> <p>Overall, the problem of obstetric fistula as highlighted in this article provides a sound argument based upon which public health and maternal neonatal health experts may build their research and focus in solving the problem of obstetric</p>
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					<p>fistula in the developing world.</p> <p>Similarly, Cook et al. (2004a) outlined the human rights link of obstetric fistula; Human Rights Watch report of 2010 placed the problem within the human rights context in Kenya (Human Rights Watch, 2010). Globally, authors like Paul Farmer have situated the right to reproductive and other health within the human rights lens (Farmer, 2008a).</p>
Human Rights Watch 2010.	<p>“I Am Not Dead, But I Am Not Living” Barriers to Fistula Prevention and Treatment in Kenya.</p> <p>New York, USA: Human Rights Watch.</p>	<p>Field research</p> <p>N=53 women with fistula</p> <p>Key informants – surgeons, nurses, teachers, NGOs, councillors, government officials</p>	<p>A human Rights Report on how obstetric fistula violates human rights.</p>	<p>Quote: “The Kenyan state violates the rights of fistula sufferers in multiple ways, by denying them their internationally-guaranteed access to the <i>highest attainable standard of health</i>, to health information critical to women’s and girls’ wellbeing, to their reproductive and Maternal health, and to a remedy for the injustices and denial of service that they face.</p> <p>areas that require increased attention in order to improve maternal health care and reduce obstetric fistulas: access to family planning</p>	<p>Triangulation of data sources is a strength of validating data obtained</p> <p>The report draws on basic human rights and international treaties that Kenya has ratified to demonstrate how the problem of obstetric fistula, and general maternal health has been neglected.</p>

				information and services, the provision of school-based sexuality education, access to emergency obstetric care including referral and transport systems, overcoming economic barriers to maternal health care services and fistula treatment, and health system accountability	
WALL, L. L. & Arrowsmith, S. D. 2007.	The “continence gap”: a critical concept in obstetric fistula repair. <i>International Urogynecology Journal</i> , 18, 843-844.	Review		<p>Authors report that although fistula surgery results in at least 80 to 95% successful closure, closure of the hole in does not always lead to continence.</p> <p>In 15% to 20% of these women whose fistula has been closed remain incontinent, a concept referred to as the ‘continence gap’. Wall attributes this to probable causes such as damage to bladder innervation, a shortened scarred bladder, or effects in the continence mechanism in the urethra and neck of the bladder.</p> <p>The author suggests that evidence based medicine would include documenting successful closure with or without continence as a true reflection of surgical outcomes.</p> <p>Wall also points out other aspects of the obstructed labour injury</p>	<p>The authors point to the need for treating the whole individual, in addition to physical healing of the fistula hole and the ensuring that other elements of damage in obstructed labor injury complex- of foot drop, infertility, ulcerations, scarring and psychological trauma are treated. The fate of women who experience residual urinary incontinence is focussed on in the recovery period.</p> <p>The issues raised here address the recovery period of fistula patients and regaining normal lives with focus on the reintegration period. Often, healthcare provides as the authors of this paper are best placed to predict and address the needs of patients in totality. The article is important in pointing to the reality of the complex nature</p>

				<p>complex that fisula surgeons ought to address, namely, vaginal stenosis that lead to difficult sexual relations; psychosocial trauma akin to post traumatic stress disorder; desire to beget more children against dismal obstetric outcomes after fistula surgery; and reintegration back to societies that may have treated them badly.</p> <p>Holistic care of the fistula patient is implied.</p>	of fistula treatment
<p>Wall, L. L., Arrowsmith, S. D., Briggs, N. D., Browning, A. & Lassey, A. 2005</p>	<p>The obstetric vesicovaginal fistula in the developing world.</p> <p>Obstetric Gynecology Survey, 60, S3-S51.</p>	<p>Committee report</p>	<p>Presents a summary of current knowledge on obstetric fistula and challenges presented by the condition</p> <p>Present clarion call for further work and research</p> <p>Chapter provides the pathophysiology of</p>	<p>The report observes that developed countries have eradicated obstetric fistula through efficient and effective systems of maternity care with access to emergency obstetric care during obstructed labour.</p> <p>Note that obstetric fistula is common in areas where maternal mortality is high and obstructed labour is a major contributor to maternal death, hence directly linked to maternal mortality.</p> <p>Authors argue that the prevalence of obstetric fistula is underestimated</p> <p>In pathophysiology of obstetric fistula formation, the obstructed labour injury complex cause damage to the urinary system</p>	

			<p>Obstetric fistula formation</p> <p>causing vesicovaginal fistula incontinence, renal failure, hydronephrosis; gynecologic injury leading to amenorrhea, vaginal stenosis, cervical damage, secondary pelvic inflammatory disease and infertility; gastric system injury leading to rectovaginal fistula and rectal sphincter damage; neuronal injury and social consequences – isolation, divorce, depression, poverty, malnutrition; and dermatologic damage</p> <p>Authors make recommendations on how dedicated fistula repair centres should run, recommending capacity building and supplies as being at the core of care for fistula patients.</p>	
Elneil, S. 2010.	<p>Obstetric fistulae in the developing world.</p> <p>African Journal of Midwifery and Women’s Health, 4, 30-32</p>	Review on obstetric fistulae		<p>Elneil argues that obstetric fistula was once suffered by women in the developed world but due to economic and health development, these phenomena has been eradicated in the developed world. The author highlights recent developments in the global arena that have initiatives aimed at training and education in preventing and curing obstetric fistula by developing a unified</p> <p>The article discusses obstetric fistula prevention and treatment at the macro level of global health. Though not context specific, the authors offer insight into what concerted effort in prevention and treatment should look like in eradicating obstetric fistulae in the developing world.</p>

				classification and using evidence-based learning as a tool. The author points to the importance of the modern approach to managing fistula in achieving the WHO objective of ‘health security for women throughout their life span’.	
Mohammad, R. H. 2007. Nigeria	A community program for women's health and development: Implications for the long-term care of women with fistulas. <i>International Journal of Gynecology and Obstetrics</i> , 99, S137-S142.	Project impact evaluation at 7 years (summative)	To describe the successes of FORWARD (Foundation for Women's Health Research and Development) project	Author deems appropriate interventions against obstetric fistula as being that which caters for the damage – physical, social, mental and economic – away from the hospital with few staff and dealing with emergencies Describes FORWARD Project that provided holistic care – surgery and rehabilitations, and skill development; and to prevent fistula, empowerment campaigns on women's literacy, civil and political rights and health committees in communities for women and their families' health Participants post op have <ul style="list-style-type: none"> ▪ a live- in centre provided with nutritious meals ▪ Literacy and vocational training in knitting, sewing, soap making, animal rearing ▪ Small business management skills ▪ Graduation I 10 months 	The strength of this programmatic evaluation is the author's acknowledgement that comprehensive care of fistula patients cannot start and end in hospital at reparative surgery, acknowledging the limited capacity of hospitals. The project suggests as shift in fistula care to that which involves communities and nongovernmental organisations partnering with medical associations and social department. The combination of prevention and reintegration in the same program is what the WHO envisions in its guidelines and this project is an example of a holistic approach; so far the only reported. Offers cost estimation of USD 2640 in reintegration and follow up program The women and girls that the author describes as roaming the streets and afraid to lose their

				<ul style="list-style-type: none"> Loan (in kind) upon graduation <p>Follow up and outreach visits on reintegration and technical support Women were often more empowered than before the illness Irreparable fistula still an impediment to reintegration and resulted in 3 women moving away from home community</p>	<p>freedom, might be the newly integrating women that my study established,; women who are not keen on returning to home and previous social settings but starting a new life elsewhere.</p> <p>Another limitation is that the project is context specific to a state in Nigeria and may not be fully transferable to other African countries. However, it offers insight on how comprehensive and holistic care of fistula patients that is aimed at reintegration can be obtained.</p>
<p>Drew, L., Wilkinson, J., Nundwe, W., Moyo, M., Mataya, R., Mwale, M. & Tang, J. 2014.</p> <p>Malawi</p>	<p>Long-term outcomes for women after obstetric fistula repair: A qualitative study.</p> <p><i>Annals of Global Health</i>, 80, 226.</p>	<p>In-depth interviews</p> <p>N= 20 women</p> <p>Content analysis</p>	<p>Explored 3 domains: Quality of life before and after fistula repair. Reproductive intentions and marriage Understanding of fistula</p>	<p>Women were 1-2 years post-surgical repair 45% reported urinary incontinence. <i>Reported improved QOL</i> since surgery – themes: Increased sense of freedom and peace; improved confidence; improved relationships with family and friends; increased community involvement; increased income generating ability. Almost half were welcomed back and had no problems <i>reintegrating</i> <i>Concerns</i> post op were – financial challenges, need for additional surgery, husband marrying other</p>	<p>It may be context specific that in Malawi stigma is not a huge problem for fistula patients and they have no problems reintegrating back. The authors call for addressing marital and future fertility issues are common in other studies including my findings. That surgery improves quality of life after surgery is a positive finding, however, the ensuing residual incontinence is a possible source of challenges to women after surgery. The authors however do not comment on how women with incontinence cope after</p>

				wives, desire for a husband and children. <i>Understanding</i> – although most understood VVF as caused by delay in seeking a health centre during labour, there were myths about witchcraft in the community	surgery and whether this affects their reintegration process.
Cook, R. J., Dickens, B. & Syed, S. 2004	Obstetric Fistula: the challenge to human rights. <i>International Journal of Gynaecology and Obstetrics</i> , 87, 72-77.	Review and commentary		Failure by states to prevent fistula and to provide repair to women with fistula is a violation to human rights to reproductive health care; and a violation of key international treaties on human rights ratified by the same countries At times countries are genuinely poor, but most prioritise other things like militarisation over health and safe motherhood Note that existing burden of obstetric fistula in developing countries is due to low prioritisation of health supplies, in addition to early marriage and pregnancy and residence in rural and remote areas Note that the current lack of repair is also a violation of human dignity Report physical, social and psychological factors of living with fistula illness Medical response should be to prevent OF through availability of	The authors make a strong point to the realisation of women's human right to optimal reproductive health and the need for governments to prevent fistula through emergency obstetric care and a fistula repair. The article however does not suggest on a micro scale how specific countries may achieve this, being written on a macro scale

				emergency obstetric care and repair, noting few fistula surgeons on the African continent Social and psychological support	
Kayondo, M., Wasswa, S., Kabakyenga, J., Mukiibi, N., Senkungu, J., Stenson, A. & Mukasa, P. 2011. Uganda	Predictors and outcome of surgical repair of obstetric fistula at a regional referral hospital, Mbarara, western Uganda. <i>BMC Urology, 11, 23.</i>	Prospective observational study N=77 women	Outcome of fistula surgery Factors that predict outcomes of repair	Authors report womens characteristics as mostly primiparous 41.6%, with a form of education 61% and were still married in spite of having fistula 45.5% With mean labour duration 2,5days and Although 76.6% delivered in a health facility- most had CS 59.7% and instrumental delivery 10.4% and perinatal mortality was 90%. Stress incontinence is common even among closed fistulas at 21.9% Authors conclude that large fistula size, circumferential fistulae and marked vaginal scarring are predictors for unsuccessful fistula repair Urethral involvement, circumferential fistulae and previous unsuccessful repair are predictors for residual stress incontinence.	The study is important in trying to predict surgery outcomes and plan for the care of fistula patients. Their main finding that has implications to the after-surgery-care of fistula patients is the presence of stress incontinence in closed fistulas [successful repair]. The success of repair may need to be defined beyond clinical outcomes to what this implies to the individual who has to live with stress incontinence for the rest of her life. The authors prediction criteria is useful in anticipating the needs of patients post repair and in planning their assistance for reintegration Being a clinical focus study, the authors report is thus limited and does not comment on the holistic physical, social and psychological wellbeing of patients; nor do they mention the contextual socioeconomic environment within which patients immerse.

					Previous unsuccessful repair being a predictor of residual stress incontinence is an implication to the health seeking behaviour of fistula patients; if this information is given to them, they may shy away from multiple surgeries after the first failed attempt, knowing well that even if the fistula is closed they still would be incontinent.
Ladeisha Lombard, Jorre, JS, Geddes, R El Ayadi, A Grant, Liz (2015) Sub-Saharan Africa	Rehabilitation experiences after obstetric fistula repair: Systematic review of primary studies <i>Tropical Medicine & International Health</i> 20(5): 554-568	Systematic review (of primary qualitative studies) Using CASP N= 10 studies	Long term emotional, physical and social economic consequences of fistula; Rehabilitation	The most important rehabilitating factor for women was fulfilment of social roles. However, emotional, physical and economic consequences of fistula challenge this process. Authors noted that health care provider perspectives were more common than patient's perspectives. Both patients and health care providers emphasised on <i>counselling</i> and <i>health education</i> as common recommendations/ interventions <i>Other post repair rehabilitative interventions included:</i> IGA, Gifts as soap, paid for transport to follow up visits, basic literacy, small money stipends, Home and religious support through food, fetching water,	A systematic review is a source of strong method of collecting evidence on any given topic from existing literature. No theoretical framework reported for examining reintegration Reintegration issues explored revealed Gap between HCP views and women's recommendations on reintegration that focus on community and social. This finding is suggestive that studies should focus on patients experiences of reintegration to determine their needs, than on the views of HCPs. However, the health care providers may be in a better position to suggest how to address these needs, for instance, when women complain of

				<p>cleaning their houses, microcredit social banks for small business capital,</p> <p>Reintegration through a broad social approach</p> <p>Community centred projects e.g. FORWARD – Community awareness campaigns, individual and group counselling and education, peer support activities.</p> <p>Multi-sectoral and action oriented approaches are good examples of successful fistula programmes.</p> <p>Authors call for broad, action oriented research focusing on the needs of women post repair, from a women’s perspectives, to develop and evaluate necessary interventions</p>	<p>infertility, health care providers can meet that need. Also, frequent complaints of women not being able to support and sustain themselves is met by the HCP observation of governments’ needs to act and prioritise women’s reproductive health as a gender equity issue.</p> <p>Authors focus on qualitative studies alone excluded likely reports on residual stress incontinence and rehabilitative outcomes.</p>
<p>Maulet, N Keita, M Macq, J (2013) Mali and Niger</p>	<p>Medico-social pathways of obstetric fistula patients in Mali and Niger: An 18 month cohort follow-up</p> <p><i>Tropical Medicine & International Health</i></p>	<p>Cohort study (Prospective follow-up) Mixed method but paper reported Quantitative</p>	<p>To highlight how patients perception impact care uptake and coping</p>	<p>Authors report on longitudinal analysis of Fistula duration, Patient Mobility, No. of surgeries Care process duration , Marital status, Continence status</p> <p>4 mobility patterns in the care trajectories of fistula patients in relation to patient’s continence</p>	<p>Paper is important in highlighting the plight of patients during and after fistula surgery and care period.</p> <p>The significant finding on the time period spent on treatment as being beyond the hospital stay to include repeated surgery offers better understanding of the fistula</p>

	18(5) 524-533	only		<p>status; homebound, itinerant, institutionalised and urbanised.</p> <p>“Quest for continence” does not end with reparative surgery Recommend Holistic customised care</p>	<p>treatment models; and multiple surgeries significance to lengthening the treatment and recovery period.</p> <p>The four mobility patterns reported are characteristic of the constant movement of fistula patients. Especially noted are the urbanised women who remain near hospitals for further treatment. It however may be that they are staying away from socially stigmatising settings in their home environment in the rural areas? Or they could be starting anew, my finding on ‘newly integrating’.</p> <p>No theoretical framework reported for examining reintegration</p>
<p>Wilson, AL Chipeta, E Kalilani-Phiri, L Taulo, F Tsui, AO (2011)</p> <p>Malawi</p>	<p>Fertility and pregnancy outcomes among women with obstetric fistula in rural Malawi</p> <p><i>Int J Gynaecol Obstet.</i> 2011 Jun;113(3):196-198.</p>	Qualitative	<p>To assess the fertility and pregnancy experiences of rural Malawian women living with obstetric fistula and following surgical repair of</p>	<p>Of the 32 affected women interviewed, 17 (53.1%) conceived after developing obstetric fistula: 13 before repair and 6 after repair (with 2 conceiving both pre- and post-repair).</p> <p>Complaints of infertility were more frequent and urgent among women who had undergone repair than among those who had not.</p> <p>Over half (53.8%) of the women who conceived while living with</p>	<p>Report Infertility, Spontaneous abortion, Perinatal death as aftermath of surgery, lingering problems of obstetric fistula. The authors thus present regaining reproductive capacity as return to normalcy. These results suggest that pregnancy and its outcome after surgery should be the focus of and included in the reintegration of fistula patients</p> <p>The authors note that repeat</p>

			<p>fistula.</p> <p>Conception and pregnancy outcomes after fistula surgery</p>	<p>obstetric fistula and all of those who conceived post-repair experienced at least 1 spontaneous abortion or perinatal death. Nineteen (47.5%) of the 40 pregnancies among women living with obstetric fistula and 7 (70.0%) of the 10 pregnancies among women post-repair ended in spontaneous abortion or perinatal death.</p> <p>Authors concluded that after 2 years after undergoing surgical repair, women can continue to experience the effects of obstetric fistula, which include infertility, spontaneous abortion, and perinatal mortality.</p>	<p>vaginal fistulas could occur if women are far from hospital during labour</p> <p>c/s as optimal care for birth ; and recommend waiting areas in hospital. This suggestion is useful in technical management of subsequent pregnancies after fistula surgery.</p> <p>The authors make a significant contribution to the holistic care of fistula patients beyond surgical repair.</p>
<p>Browning, A (2009)</p>	<p>Pregnancy following obstetric fistula repair, the management of delivery</p> <p><i>BJOG: An International Journal of Obstetrics & Gynaecology</i> 116(9): 1265-1267</p>	<p>Short communication (Case series)</p> <p>N=49 pregnancies (not patients)</p>	<p>Study reports on the experience of managing Pregnancy and outcomes after fistula surgery</p>	<p>The report of 49 patients; 5 had elective c/s with live babies, of the 41 with caesarean section, one had twins, one had a delayed c/s after 6 hours of labour and had stillbirth; 3 were vaginal deliveries, 1 precipitate labour with live birth but two premature at 30 and 26 weeks who died.</p> <p>There were no recurring obstetric fistulas but three babies were lost</p> <p>But author report that there were</p>	<p>The author has demonstrated from his findings that</p> <ul style="list-style-type: none"> ▪ Return to reproductive capacity ▪ Repeat vaginal fistulas could occur if far from hospital during labour ▪ c/s as optimal care for birth <p>The authors make relevant recommendations for ; waiting areas in hospital for women who have had fistula surgery during late pregnancy to avoid recurrence or stillbirth and neonatal death.</p>

				<p>other 24 women who presented with repeat fistula after successful surgery and subsequent delivery, because they did not come to the waiting unit for C/S and had unassisted prolonged labour and delivered at home or thereafter presented at another facility for delivery. Reasons for delay were they lived far away, were not given permission, were afraid of operation. Or the labour was too quick.</p>	<p>This article is valuable in documenting pregnancy and birth outcomes after fistula surgery. Women desire and do get children after fistula surgery and this reality then calls for careful monitoring of women during subsequent pregnancies. The positive outcomes under supervised delivery and C/S at Hamlin hospital offer good suggestion to stand alone fistula centres around the globe; they may offer treatment but also be centres of prevention from further fistula occurrence.</p>
<p>Turan JM Johnson, K Polan, ML (2007) Eritrea</p>	<p>Experiences of women seeking medical care for obstetric fistula in Eritrea: Implications for prevention, treatment and social reintegration <i>Global Public Health 291): 64-77</i></p>	<p>Qualitative interviews N=26 11 new fistula patients and 15 returning patients 5 family members</p>	<p>Interviews designed to generate information for community education and mobilization on safe motherhood To improve women's medical</p>	<p>Women in the follow up after surgery were aged 17-37 years; 53% were divorced, majority were illiterate. New fistula patients described lack of transport and delay in recognising the seriousness of their condition during labour as two factors that led to their delay in seeking emergency obstetric care in labour. Returning patients reported improved conditions Both new and returning patients lacked awareness on the condition</p>	<p>Qualitative methods best suited to document patients experiences and triangulation of data sources is a strength to this qualitative research. Authors do not comment on fertility or return to reproductive concerns of women post repair, nor do they report any pregnancies. Being a qualitative study with small sample, it is likely that only those with continence problems returned, but the aftermath of those who had no problems is not accounted for. In a study of</p>

			<p>and social services Follow up care</p>	<p>and authors recommend standardised information and counselling packages for fistula patients Post operatively, patients had residual incontinence and sexual health problems</p>	<p>reintegration as mine, we present results from both women who are continent and women who are not continent.</p>
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Appendix 12: Budget

ITEM	QUANTITY	COST PER UNIT (Ksh)	TOTAL (Ksh)	COST IN USD
Field research Services				
Transport	12	8,000	96,000	1156.6
Translation	1	40,000	40,000	481.9
Transcribing	1	60,000	60,000	722.9
Communication	12	1,000	12,000	144.6
Allowances				
Research assistants	2*5 months	25,000	250,000	3012.0
Researcher stipend	12 months	50,000	600,000	7228.9
Equipment				
Digital voice recorders	3	8,000	24,000	289.2
Laptop computer	2	45,000	90,000	1084.3
SPSS	1	30,000	30,000	361.4
Stationery				
Questionnaire printing and copying			9,300	112.0
Proposal Printing & Binding	6	5,000	5,000	60.2
Pens, Notebooks, carry bags	1	5,000	5,000	60.2
Thesis printing and binding	6	5,000	5,000	60.2
Research ethics & Permits				
Research ethics	1	5,000	5,000	60.2
MOEST	1	5,000	5,000	60.2
Conference costs				
	1		40,000	481.9
TOTAL			1,276,300	15377.1
Contingency	5% of total cost		63,815	768.9
GRAND TOTAL			1,340,115	16,146