

THE UNIVERSITY OF HULL

Experiences of Women with Obstetric Fistula in Nigeria: A Narrative Inquiry

A Thesis Submitted to the University of Hull in Fulfilment of the Award of
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By

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DEDICATION

In loving memories of
my beloved husband,
Abraham Degge (who believed in me and set me on the path to doing a PhD)
and my beloved son
Boyesoko Degge (too wonderful a son to be forgotten)
And to the
brave women,
who shared their stories-
“A voice to make maternal healthcare accessible to all”

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ABSTRACT

Obstetric Fistula is an abnormal opening between the vagina and rectum resulting from prolonged and obstructed labour. It occurs mostly in developing countries and is a neglected maternal health issue in Nigeria. Women's experiences of living with fistula often reflect gender inequities. This study explored how women attending a reintegration service described their experiences of living with fistula. Using narrative inquiry methodology, 15 women (treated and rehabilitated) were interviewed. Data were analysed using the core story creation and emplotment method of narrative analysis. A reconstructed narrative provided plot headings of 'fistula ordeal, treatment process, and returning to life'. Fistula formation was linked to the influence of others, geographical remoteness and transport and poor health systems. Fistula survivors and families facilitated access to treatment; aided to cope with incontinence that triggered stigma issues. Negative identity changes through incontinence were: 'Leaking' identity, 'Masu yoyon fitsari' (the leakers of urine identity), and 'spoiled' identity. Attending the repair centre conferred hope and relief through mutual survivors ('Masu yoyon fitsari') support. 'Spoiled' identity reflected the challenges of the 'leaking' identity in the face of 'failings' as a woman with respect to sexual and reproductive responsibilities. Reversing the negative identities was pivotal in the women's resilience in seeking a cure. The 'improved' identity achieved after fistula repair and rehabilitation provided continence control and improved financial status. This research is the first known comprehensive empirical study of the experiences of treated and rehabilitated obstetric fistula survivors in Nigeria. The prevalence of fistula in Nigeria reflects inequitable distribution of health care compounded by socio-cultural practices. This research is the first application to women's health in the African context using Frank's narrative typology. The study contributes to the empirical evidence of women's pathway through developing fistula, to treatment, and rehabilitation into family and community life in Nigeria.

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LIST OF ABBREVIATIONS

ANC	Ante natal care
EmOC	Emergency Obstetric care
DHS	Demography Health Survey
FGC	Female Genital Cutting
FGM	Female Genital Mutilation
FMoH	Federal Ministry of Health
MDG	Millennium Development Goals
MMR	Maternal Mortality Ratio
MWH	Maternal Waiting Home
NOFC	National Obstetric Fistula Centre
OF	Obstetric Fistula
PHC	Primary Health Centre
SDG	Sustainable Development Goal
SBA	Skilled Birth Attendant
TBA	Traditional Birth Attendant

RESEARCH/ PUBLICATIONS

1. **Degge, H. M.**, Hayter, M, and Laurenson, M. (2017). An Integrative Review on Women Living with Obstetric Fistula and After Treatment. *Journal of Clinical Nursing*. 26 (11-12), pp 1445-1457.
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1. **Degge, H.M.**, Hayter, M., Laurenson, M. Reflections on Identities; Obstetric Fistula Survivors' Lived Experience Narratives. In preparation
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2. Insights from birthing experiences; obstetric fistula survivors' narratives. **H. M Degge**, M. Hayter, M. Laurenson. Oral presentation. 3rd Annual Public Health PhD Symposium, Liverpool John Moore University, Liverpool, UK.13th-14th July 2017
3. Negotiating the pathway of recovery; stories by rehabilitated fistula survivors. **H. M. Degge**, M. Hayter & M. Laurenson. Oral and Poster presentations. Spotlight Conference, Faculty of Health Sciences, University of Hull. 5th Jan 2017

4. Negotiating the pathway of recovery; stories by rehabilitated fistula survivors. **H. M Degge**, M. Hayter, M. Laurenson, video presentation. International Conference on Narratives of Health and Illness. 11th-12th Nov, 2016. Tenerife, Spain

5. Systematic review; Lives and experiences of women with obstetric fistula. Oral presentation. International Conference on Public Health, **H. Degge**, M. Hayter, M. Laurenson, Colombo, Sri Lanka. 13th-14th May, 2015

CHAPTER ONE

INTRODUCTION AND BACKGROUND TO STUDY

1.0 Introduction to Chapter

This chapter consists of two sections, A - Introduction of Study and B – the Research Context. Part A begins by providing a summary of how the chapters of the thesis are structured and then it looks at the motivation for the study. The part B provides the research context of the study. It describes maternal health issues in developing countries and then it considers maternal morbidity with a focus on obstetric fistula. The chapter also looks at obstetric fistula in Nigeria.

PART A: Introduction of Study

1.1 Thesis Overview

The thesis is structured into seven chapters:

Chapter One - Background of the Study: This chapter looks at the structure of the thesis and what motivated the study and it also describes the research context on the research topic; in this section the discussion commenced on maternal health issues in developing countries, it then focuses on obstetric fistula in sub-Saharan Africa. The chapter concludes with a discussion on maternal health issues and obstetric fistula in Nigeria, the study country.

Chapter Two- Systematic Literature Review: The chapter discusses the systematic review of literature that was carried out using the PRISMA framework. Twenty-five articles met the inclusion and exclusion criteria that guided the selection process. The findings from the selected articles are discussed thematically, also the methodological quality of the articles are critically analysed in this chapter. Based on the discussions of the findings, the gaps identified are used to guide the choice of the research question for the study. The research question and study objectives are presented to conclude the chapter.

Chapter Three- Methodology of the Study: This chapter discusses the rationale behind the choice of a qualitative research method and the philosophical assumptions guiding qualitative research. It then discusses narrative inquiry, justifying why it was selected as the research method. The chapter also provides the details of the guiding theoretical framework of narratives, methods of data collection and data analysis as well as narratives approaches in health and illness experiences; along with examples of researches that have employed narrative inquiry. The chapter discusses the principles governing the research method and ethical considerations that would be followed for the study.

Chapter Four – Method: The chapter presents the research question and study objectives. It also provides the description of the study design and how the research was conducted; this includes the description of the study site, sampling technique, and method of recruitment. In addition, details of data collection and ethical procedures followed are presented in this chapter. Furthermore, a description of the data analysis technique and a worked example of the data analysis matrix are included in this chapter.

Chapter Five – Findings: This chapter presents the findings of the study; in the first section a table with the demographic information of all the participants were presented. The second section features an abstract of a core story that was selected as a case study. The third section outlines the collective narratives, presented in a narrative format along three plots lines; namely the fistula ordeal, treatment process and returning to life.

Chapter Six - Discussion: This chapter discusses the key findings in the light of the research question. The chapter is divided into two sections, the first section examines the findings in relation to existing literature while the second section, discusses findings along theoretical concepts identified in the study.

Chapter Seven- Conclusion: The final chapter summarises the findings of the study and the role of the researcher's reflexivity. This chapter highlights the contribution to knowledge as well as the implications and recommendations for practice, policy and research. The limitations of the study are also outlined and discussed.

1.2 Rationale for Study

Trained as a Pharmacist (1990 graduate), my area of practice was mostly in the community/retail pharmacy. While in practice, I was more interested in counselling to reduce repeat visits to the pharmacy for the same health problems and conducting community outreach that promoted health. The desire to enhance my practice motivated me to enrol in the fellowship training of the West African Postgraduate College of Pharmacists, Lagos (2004-2007). This was my first structured contact with public health promotion. I was challenged then by the information that there was a paradigm shift from curative to preventive health care practice. This contact thereafter changed my practice pattern to a more public health driven approach. Thereafter, I broadened my professional role to serve as a volunteer program manager for a Non-Governmental Organisation – Total Health for All Initiative (THAI) that was involved in community health promotion activities. My major roles were to develop programs and organise seminars and training workshops with a focus on HIV prevention; this included mobilizing and sensitizing the community in HIV Counselling and testing (HCT); I was responsible for carrying out training of community volunteers in carrying out advocacy and HCTs. Another major activity I did was organizing and coordinating Health clubs in five secondary schools in Jos, Nigeria. The main aim of this club was to develop healthy lifestyle in youths through developing life skills and mentoring for aspiration for higher education.

The exposure working with THAI provided the opening to work, when the opportunity arose as an on-site consultant from 2008-2010 for an international organization, Howard University- Pharmacy and Continuing Education project under the Global HIV AIDS Initiatives in Nigeria (HU/PACE-GHAIN) a USAID funded project. My main responsibility was to provide on-site training and mentoring to rural health facilities involved in delivering comprehensive HIV and Prevention of Mother to Child Transmissions (PMTCT) services. In addition to training the point of services staff in carrying out effective and efficient services, my other responsibilities included developing the capacity of People living with HIV (PLHIV) for optimal treatment adherence and engaging the community to utilize the HIV services and to stop stigma and discrimination of PLHIV.

This experience exposed me to the significant maternal health needs in rural communities, in North East and North Central zones of Nigeria. This encounter stimulated the desire for a change in career and the need to be better equipped to practice as a public health professional, which motivated me to obtain the Master of Public Health (MPH) degree at the University of Leeds in 2010-11. After the completion of my MPH, I got a job as a lecturer with Bingham University (BHU), Jos, Nigeria in the Department of Community Medicine and Primary Health Care, College of Medicine. My main roles were to prepare and deliver lectures, prepare and score tests/assignments, organize field trips, coordinate rural postings to rural Primary health centres and supervise medical students. In addition to my teaching assignments, I was involved in research collaboration with the Evangel Vesico Vaginal Fistula (EVVF) Centre of the Bingham University Teaching Hospital, Jos, Nigeria.

My work and personal experiences over the years as a health professional in Nigeria provided the motivation for this study. The main impetus came about while I served as an on-site consultant with HUPACE/GHAIN. This assignment was my first encounter with poor standard of health services and gender inequities in the society with respect to maternal health for rural women. I observed at first hand while working in the rural health facilities and interacting with the community the discrimination women faced as a result of socio-cultural factors that limited the women's access to health care. For instance, there were cases of women whose husbands restricted them from seeking care after testing HIV positive. Unfortunately, in most instances, the husbands were aware of their own status and were already on Antiretroviral (ARVs). In Nigeria routine HIV counselling and testing (HCT) are provided during antenatal care (ANC), and upon receiving a positive test result, many such women would be divorced and sent out of the home. Additionally, the rural health facilities were poorly equipped and staffed; equally in the case of an emergency, they lacked good referral system to access specialised care that is usually located within the urban centres. None of the facilities I worked in had functional ambulances. Moreover, in most of the remote communities there were no pharmacists to dispense ARVs and most often than not, the facility did not have a Doctor.

The quality of health care service delivery and the compounding socio cultural factors got me rethinking on the need for a career change towards teaching and research in the field of public health, particularly in women's reproductive health. As a woman I experienced the need for emergency obstetric care as a result of childbirth in 2000 when I suffered a Post-Partum Haemorrhage a few minutes after delivery. The teaching hospital I had my ante natal care had gone on strike the week of my expected delivery date (EDD), and so when labour started I went to a private clinic. Luckily for me there was a surgeon there who battled to save my life. This experience led me to wonder what could have been my fate if I was a woman living in the rural area with no money to access private care or if no doctor was available in the rural clinic (as is often the case). This led me to thinking about the health care provision changes needed to ensure women's needs were recognised and met.

The climax to this desire to make a change came in 2009, when I lost my 14 and half years old son after a brief illness. I experienced the poor health services in Nigeria and noted that Nigeria's leaders and rich sought health care outside the country. Up until my son's death, no conclusive diagnosis was made and the histopathology results to determine his course of treatment arrived 5 weeks after he had died. While he was hospitalised, I used all my resources as a health professional to negotiate the care he needed, but this was to no avail. This realisation highlighted that even with all my professional expertise the care system still failed my son. This then led me to wonder if this was the same for other women especially if they were less qualified or had less health care knowledge. This traumatic experience reaffirmed my commitment to effect health care change for women through teaching and research.

The desire to pursue a doctoral study focussed on maternal health issues was stimulated by my personal and professional experiences. While training in public health at the Nuffield Centre of International Health and Development, University of Leeds, UK, I finally identified gender inequities in health care access as a major driver of poor reproductive health outcome among women in my country. Consequently, the need to address this disparity became a matter of priority for me. Equally important to me in this experience was the realization the huge role that socio-cultural factors had to play on those unacceptable poor health indices in my country. The poor maternal health indices

were put into better perspective and more importantly, was the realisation that most of these health issues are preventable and avoidable.

My primary training as a pharmacist with the concept of patient-oriented care approach and the on-field exposure on health disparity set me on the path to contribute towards addressing social injustice. Coming from the northern part of Nigeria which is the highest contributor to the maternal health indices and having worked and seen at first hand the experiences of women in some of the rural communities was a strong motivating factor. The shift for me from HIV came because of the disparity I observed; HIV affects everyone regardless of wealth, age and sex, but obstetric fistula my main research study interest is termed the 'disease' of the "poorest of the poor" women. Furthermore, HIV has received so much attention and funding from the Western world, while fistula remains at the bottom of the agenda of reproductive health issues. It does not cross borders like Ebola or HIV or even Female Genital Mutilation (FGM); it is restricted to regions of the world where socio-cultural practices, environmental issues and political non-commitment encourage poor health care systems. This is a major concern to me and is one of my motivations to effect a change as a public health professional and instructor.

PART B: Research Context

1.3 Maternal Health Issues in Developing Countries

Maternal health refers to the health of women during pregnancy, child delivery and post-partum. Every woman that desires a baby wants to have a safe delivery, care and support throughout pregnancy, during and after delivery (Koblinsky et al., 2006). For safe delivery, access is required for a range of care that includes supportive and vigilant waiting to Caesarean Section (Koblinsky et al., 2006). The World Health Organization (WHO) estimates that 10-15% of all pregnancies that results in live birth, develop life threatening complications that require emergency and specialised interventions to save life or prevent lifelong disabilities (Murray and Lopez, 1998). Each year approximately 350,000 women die while pregnant or giving birth — about 1,000 a day. Of these women, 99% die in developing countries (Ronsmans and Graham, 2006, WHO, 2015). About 66% of these deaths occur in Sub Saharan Africa followed by 33% in South East

Asia, with Nigeria (19%) and India(15%) accounting for one third of these death (WHO, 2015). The life time risk of maternal death in Sub-Saharan Africa is one in 36 as against one in 4,900 in developed countries (WHO, 2015). Furthermore, within countries, the wide disparity in maternal mortality is associated with wealth or social status, and location whether rural or urban (Rosenfield et al., 2007, Say and Raine, 2007).

In the International statistical Classification of Diseases and related health problems, 10th revision (ICD-10) the World Health Organization defined maternal death as the death of a woman while pregnant or within 42 days of termination of pregnancy, regardless of the site or duration of pregnancy, from any cause related to or aggravated by the pregnancy or its management (WHO, 2011). The major causes of maternal mortality and associated morbidities (table 1.1) are haemorrhage, infections, pregnancy related hypertensive disorders, and delivery/terminations, while indirect causes are cardiovascular diseases or diabetes, malaria or HIV/AIDs (Murray and Lopez, 1998, Ronsmans and Graham, 2006, Chou et al., 2016, WHO, 2016).

Maternal health issues have long been topics of discussion in international health due to the vulnerability of women. The international health strategy to address maternal health has evolved over the years to address these issues. The Safe Motherhood initiative was launched in 1987 to mobilise support to address high maternal mortality in developing countries (Rosenfield and Min, 2009). The strategies adapted for this initiative was screening for high risks mothers during ante natal care and training of Traditional birth attendants (TBAs) for safe and hygienic practices during child birth (Rosenfield and Min, 2009). The lack of meaningful progress with the Safe motherhood initiative triggered the need to broaden the approach of addressing maternal health (Rosenfield and Min, 2009, Maclean, 2010). The significant change occurred at the 1994 International Conference on Population and Development (ICPD), where the provision of reproductive health was adjured to be operationalized through a human rights based approach (Rosenfield and Min, 2009). The inclusion of maternal health within the United Nations Millennium Development Goals (MDG) in 2000, was a highly significant achievement (Rosenfield and Min, 2009). The interlinked relationship between the goals implies that Goals 1,3, 4, and 6 contributes towards improving maternal survival (Filippi

et al., 2006, Starrs, 2006, Maclean, 2010) while goal 5 was directly related to reducing maternal mortality (Filippi et al., 2006).

Decline in maternal mortality has customarily been used as a critical gauge of progress in improving maternal health. The ICPD called for a decline by half of maternal deaths by 1990 and the remaining half by 2015. The MDG goal 5 targeted a 75% reduction in maternal mortality for 1990 -2015 to improve maternal health. In addition, even more recently at the expiration of the MDG the new global focus via the Sustainable Development Goal (SDG) goal 3.1; maternal mortality reduction remains the focus (UNDP, 2017). However, depending solely on maternal mortality to evaluate a country's maternal health status discounts the importance of maternal morbidity. Maternal morbidity is not only a precursor to maternal mortality but also equally a probable cause of lifelong disability and low quality of life (Ronsmans and Graham, 2006, Filippi et al., 2007, Firoz et al., 2013).

Maternal deaths have been depicted as the “tip of the iceberg and maternal morbidity as the base” (Firoz et al, 2013: 794); for every woman that dies, 20 to 30 women suffer pregnancy related acute or chronic morbidities (Donnay, 2000, Geller et al., 2006, Rosenfield et al., 2007, Firoz et al., 2013). The progress in achieving the reduction in maternal mortality target was reportedly slow for countries in Sub-Saharan Africa and south-East Asia, even though globally there was a 44% reduction in maternal mortality ratio (WHO, 2015). The current global estimates on maternal mortality reflect the role indirect conditions, contribute to maternal deaths (Chou et al, 2016). In achieving the Universal Health Coverage (UHC) focus of the SDGs, attention needs to be given maternal morbidity in addressing the health, productivity and dignity of women (Langer et al., 2013, Chou et al., 2016).

1.4 Maternal Morbidity/Complications

The exact prevalence of maternal morbidity is unknown, as data on incidences are largely undocumented (Wall, 2006, Koblinsky et al., 2012, Firoz et al., 2013) but the World Health Organisation, estimated that 8 million women suffer pregnancy related complications yearly (Wall, 2006, WHO, 2010). Lack of accurate data on prevalence has been attributed to the absence of a common definition and standardised criteria for

identifying morbidity, with poor health information systems to capture vital data (Hardee, 2012, Koblinsky et al., 2012, Chou et al., 2016). Due to lack of standardisation in definition and identification of cases, WHO commissioned a four-year project-The Maternal Morbidity Working Group (MMWG) for this purpose (Firoz et al., 2013, Chou et al., 2016). The MMWG developed a framework for identifying maternal morbidity and defined maternal morbidity as: “any health condition attributed to and/or aggravated by pregnancy and childbirth that has a negative impact on the woman’s wellbeing (Firoz et al., 2013, Chou et al., 2016).

The causes of maternal morbidity are numerous and complicated, varying in duration and gravity and covering a broad span of diagnoses requiring a vast array of treatments (Ronsmans, 2009, Hardee, 2012, Firoz et al., 2013). These morbidities have diverse aetiologies and some of which are associated with the quality of care provided during pregnancy and childbirth, and others to a wider set of social, personal and other factors beyond the health system (Hardee, 2012, Chou et al., 2016). Therefore, maternal morbidity can be conceptualized as a spectrum ranging, at its highest severity, from a “maternal near miss”; this aspect is defined by the World Health Organization (WHO) as, “the near death of a woman who has survived a complication occurring during pregnancy or childbirth or within 42 days” of the conclusion of pregnancy – to non-life-threatening morbidity, which is the most common (Say et al., 2004, Firoz et al., 2013).

These disabilities are tragic because they are often totally preventable. Additionally, disabilities resulting from childbirth affect the health and productivity of women who are in the peak of their lives (Ashford, 2002). Three overlapping dimensions of women’s lives are affected as a result. The first is the disruption of bodily integrity through impairment, continuing ill health and reduced strength and vigour. The second is the disruption of the household economy through debts and loss of productivity. The third is the disruption of women’s social identity and stability, which could include loss of social status in the household, and community (Cook, 2004, Wall, 2006, Filippi et al, 2007, Storeng, 2010).

Maternal disabilities are strongly correlated with inadequate or non-existent medical care during child delivery and immediately after the birth (Ashford, 2002, WHO, 2017).

In developing countries just about half of all births in 2016 were attended to by Skilled Birth Attendants (SBAs - Doctor, Nurse, or trained Midwives) even though globally there was an increase in SBAs from 61% in 2000 to 78% in 2016 (WHO, 2017). Most often, women who experience complications do not receive adequate medical attention in time to avert serious illness or injury (Ashford, 2002, Lewis, 2008). Women and their families may not recognize the warning signs of complications or may fear poor treatment. Furthermore, the issues of user fees at health facilities and out of pocket expenses might hinder access (Ashford, 2002, Filippi et al., 2006, Wall, 2006, Amoako Johnson, 2016). Due to poor quality of obstetric care, deliveries in health facilities can even be risky. In some cases, the delays experienced between arriving at a health facility and receiving the necessary care can result in the death of the mother or child or the development of morbidity (Ashford, 2002, Ronsmans and Graham, 2006, Wall, 2012c).

The morbidity and associated disability can either be acute, affecting a woman during or immediately after childbirth, or chronic, lasting for months, years, or a lifetime (Ashford, 2002, Storeng et al., 2010, Chou et al., 2016). The effects of near-miss events and maternal deaths on women and their families can be considerable, and recovery can be gradual, with lingering consequences (Lewis, 2008). The long-term consequences are physical, psychological, social, and even economical (Filippi et al., 2006, Storeng et al., 2010, Koblinsky et al., 2012). Although maternal mortality has been chosen as the valued outcome for MDGs and now the SDG, health-care systems cannot overlook the untold hardship that takes place with morbidity and the continuing need for health care; principally because the frequency and duration of suffering can be incapacitating (Filippi et al., 2006). Table 1.1 below presents the five major maternal morbidities or complications and examples of ailments. One of the major morbidities is obstetric fistula; it is one of two maternal morbidities that affect the largest number of women (Hardee, 2012).

Table 1.1: Pregnancy and childbirth related complications in developing countries

Direct maternal complication	Major associated effects
Haemorrhage	<ul style="list-style-type: none"> • Shock • Cardiac failure • Infection • Severe anaemia
Sepsis	<ul style="list-style-type: none"> • Pelvic inflammatory disease • Septicaemia • Shock • Chronic pelvic pain • Damage to reproductive organs • Infertility
Obstructed and prolonged labour	<ul style="list-style-type: none"> • Fistula • Genital prolapse • Uterine rupture, vaginal tears • Nerve damage • Sepsis
Hypertensive disorders of pregnancy	<ul style="list-style-type: none"> • Shock • Cardiac failure • Infection
Unsafe abortion	<ul style="list-style-type: none"> • Reproductive tract infection • Damage to uterus • infertility • Pelvic inflammatory disease • Chronic pelvic pain

Source:AbouZhar (1998).

1.5 Obstetric Fistula a Public Health Problem

1.5.0 What is Obstetric Fistula?

Obstetric fistula (OF) is a distressing childbirth injury in which an abnormal opening develops (see figures 1 and 2) between the bladder and the vagina and or the rectum leading to urinary and or faecal incontinence (Bangser, 2006, Wall, 2006, Hardee, 2012). The most common presentation is a Vesico Vaginal Fistula (VVF); this is a hole between the vagina and the bladder in which urine leaks through the vagina (figure 1). On the other hand, Recto Vaginal Fistula (RVF) is a hole between the vagina and the rectum, in which there is leakage of faeces and flatus through the vagina (Wall, 2009, Abrams, 2012, Tebeu et al., 2012). Vesico Vaginal Fistula accounts for 79%- 100%, while Recto Vaginal accounts for 1%-8%, combination of both occurs in 1% to 23% of cases (Tebeu et al., 2012).

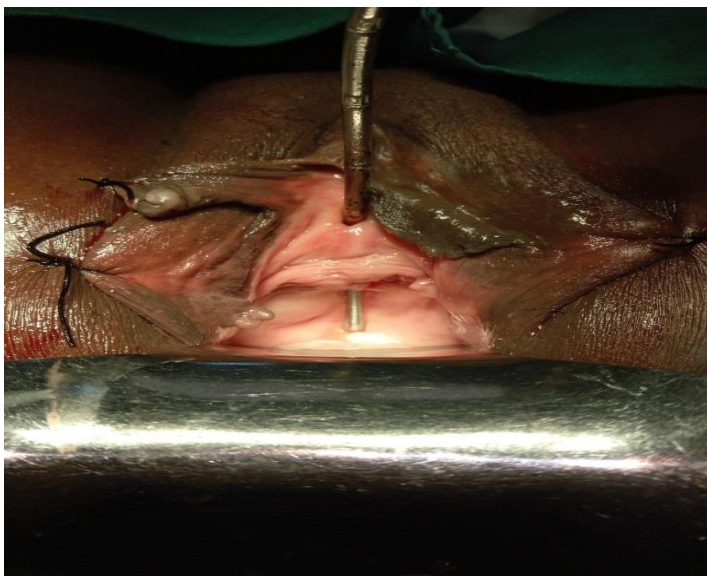


Figure 1: Small Vesicovaginal Fistula

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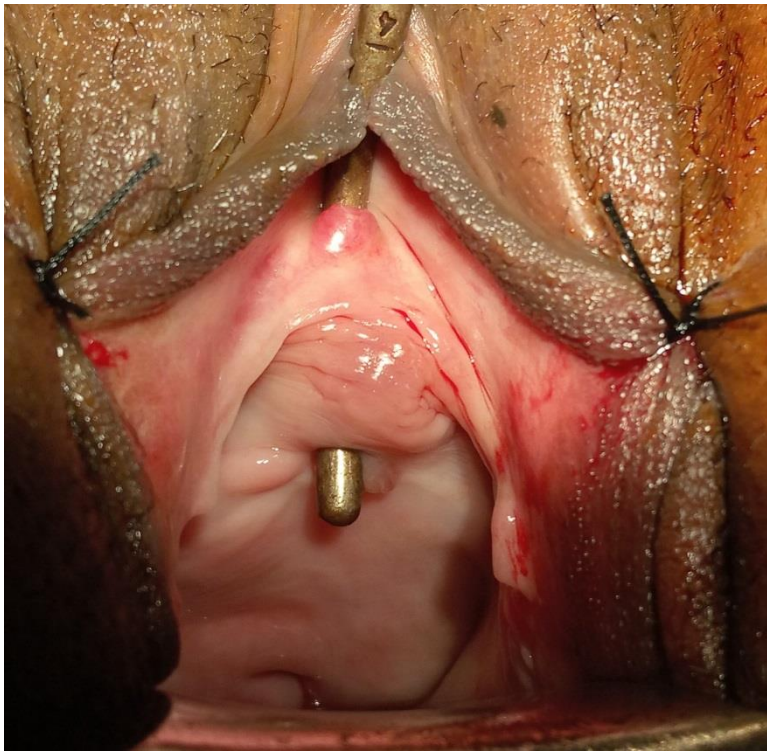


Figure 2: Medium Vesicovaginal fistula

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This condition was long eradicated in developed countries with the advancement of obstetric care; however, it remains one of the neglected forms of chronic maternal morbidity that occurs mainly in low and medium income countries (Cook et al., 2004, Wall, 2009, Hardee, 2012, Wall, 2012b). Even though obstructed labour is the major cause of obstetric fistula, it is not the only direct cause. Other causes are: instrumental interventions or surgical procedures, congenital, radiation or malignancy could lead to fistula; these usually are more predominant in developed countries (Cook et al., 2004, Abrams, 2012).

1.5.1 Demographic Characteristics of Women with Obstetric Fistula

Numerous studies have described the women with obstetric fistula; studies described women as within the age range of 9 years to 65 years, with the mean age usually less than 20 years (Wall et al., 2004, Melah, 2007, Muleta et al., 2007, Alio et al., 2011, Tebeu et al., 2012, Landry et al., 2013, Lengmang and Degge, 2017). It is also most common among the primiparous; accounting for the majority as compared to multiparous

women (Wall et al., 2004, Muleta et al., 2007, Alio et al., 2011, Tebeu et al., 2012, Lengmang and Degge, 2017). The occurrence is represented as a bimodal distribution, with the highest peak in primigravid women and the second peak for the multipara with over four deliveries most probably due to tendency of increasing foetal birth weight with subsequent pregnancies (Danso et al., 1996).

The outcome of delivery usually is stillbirth (Wall et al., 2004, Muleta et al., 2007, Tebeu et al., 2012). Women are reported to have low educational background with poor socioeconomic status (Wall et al., 2004, Muleta et al., 2007, Mselle et al., 2011b, Landry et al., 2013). Furthermore, the place of residence is usually rural (Wall et al., 2004, Melah, 2007, Muleta et al., 2007, Alio et al., 2011, Landry et al., 2013). Two recent studies in Nigeria and one in Uganda however revealed that, fistula is not limited to rural location (Phillips et al., 2016, Lengmang and Degge, 2017, Meurice et al., 2017). However, in Lengmang and Degge's study women had the characteristics of the 'typical fistula patient'; marriage at an early age and low literacy level (2017:739).

1.5.2 Causes of Obstetric Fistula in Developing Countries

The most common cause of fistula in developing countries is that due to obstruction of labour and delayed delivery; the inability of a woman to deliver her baby through the birth canal is caused by a discrepancy in the available space in the pelvic region and the foetal size (Wall, 2006). The main factors that predispose a woman to obstruction are mal-presentation of the foetus or cephalic-disproportion (Abrams, 2012). Mal-presentation can happen to any woman but most frequently occur in grand multipara, women that have had five or more deliveries with a lax uterine muscle (Abrams, 2012). Cephalic-disproportion on the other hand is when the foetus head or body is too big to pass through the mother's pelvis opening (Wall, 2006, Abrams, 2012). The obstruction leads to a prolonged pressured contact of the foetal head in the birth canal area, causes a loss of blood flow to the soft tissues of the woman's bladder, vagina and rectum (Arrowsmith et al., 1996, Wall, 2012c). Consequently, ischaemic injury leads to massive tissue necrosis in the woman's pelvis and foetal death as a result of asphyxiation; a day or two later, the dead foetus is expelled through the vagina after becoming macerated

from decomposition and subsequently afterwards the necrotised tissue gives way as a slough exposing the fistula (Wall, 2006).

Another critical factor for fistula development is the lack of access for girls and women to maternity care (de Bernis, 2007, Wall, 2009, Phillips et al., 2016). When labour becomes obstructed, the only solution to prevent the “cascade of complications” (obstructed labour injury complex) is prompt provision of emergency obstetric care (Wall, 2009: 315). Male foetus is mostly responsible for cephalo-pelvic disproportion that results into obstruction of labour for both primigravid women and multipara, due to larger foetal size and head circumference than girls at term (Muleta et al., 2010, Wall, 2012a). Women would have laboured mostly at home for several days ranging from 2.5 to four days (National Bureau of Economic Research, 2010, Muleta et al., 2007, Kirschner et al., 2010, Tebeu et al., 2012).

Childbirth is mostly guided by cultural practices and values (Wall, 1998, Jansen, 2006). As a result, women would most often attempt giving birth in the homes attended by Traditional Birth Attendants (TBAs) and family (Jansen, 2006, Women's Dignity Project and EngenderHealth, 2006, Bangser et al., 2011, Mselle et al., 2011a, Phillips et al., 2016). Some authors asserted that preference for home delivery is due to cultural beliefs and the low status of women (Wall, 1998, Roush et al., 2012); cultural beliefs such as disposal of placenta after delivery, and preference for traditional delivery posture were found to positively influence preference for home delivery in some societies (Anyait et al., 2012, Bohren et al., 2014). Furthermore, TBAs are reported to be more compassionate and considerate than health workers in facilities (Jansen, 2006, Babalola and Fatusi, 2009, Bohren et al., 2014). However, other studies arguing from fistula survivors’ perspectives claimed financial issues and transport are the major reasons for home delivery (Jansen, 2006, Women's Dignity Project and EngenderHealth, 2006, Phillips et al., 2016).

Research has shown that receiving care usually is delayed following the Thaddeus and Maine (1994) three delay framework of causes of maternal mortality (Wall, 2009).
1. Delay in taking decision to seek care. 2. Delay in arriving at the health facility. 3. Delay in obtaining the required intervention at the facility (Thaddeus and Maine, 1994, Wall,

2009). Delay one was attributed to women's lack of decision making power influenced by their low socioeconomic status and their financial capacity to pay for maternal health services (Onolemhemen, 1999, National Bureau of Economic Research, 2010, Phillips et al., 2016, Kaplan et al., 2017). Additionally, the consent of spouse was required to seek care or it was traditional practice to have child delivery at home (Onolemhemen, 1999, Wall et al., 2004, Mselle et al., 2011a, Kaplan et al., 2017). The women lived mostly in remote villages, and experienced transportation difficulties because of the distance to facility, the bad roads, the lack of a vehicle, or the lack of funds to pay transport costs. These aspects contributed to the second delay (Wall et al., 2004, Nathan et al., 2009, Bangser et al., 2011, Mselle et al., 2011a, Landry et al., 2013, Roka et al., 2013, Kaplan et al., 2017). Women also reported a further waiting period on arrival at health facilities, causing the third delay. Lack of support and negative attitudes of health professionals which could be pre-natal or during labour contributed to delay at the facilities (Nathan et al., 2009, Mselle and Kohi, 2015b, Phillips et al., 2016), that included poor referral protocols in transferring care for specialised attention were reported by women (Mselle et al., 2011a, Roka et al., 2013). The major causes of delay were the absence of skilled birth attendants and the lack of equipped facilities in rural settings to provide timely maternal health services (de Bernis, 2007, Bangser et al., 2011, Mselle et al., 2011a, Phillips et al., 2016). Furthermore there was an absence of doctors in the public sector provision as some worked in private practice (Phillips et al., 2016). Sometimes even when the facilities are available the issue of affordability of services still serves as a hindrance to access (Wall, 2009, Phillips et al., 2016). The role of the healthcare system on fistula formation will be discussed in greater detail below.

The main underlying social root cause is poverty; as highlighted above, girls and women who develop fistula usually come from poor communities with low socioeconomic background (Wall, 2012c, Abrams, 2012) where healthcare system is weak and there are limited resources for the poor to utilize health care (Bangser, 2006, Wall, 2012a, Heller and Hannig, 2017). Poor nutrition in early childhood has equally been implicated in poor development of the pelvis, causing the inability to accommodate child birth (Wall et al., 2004, Wall, 2006) subsequent improvement in nutrition during pregnancy leads to larger foetal size and the risk of cephalopelvic disproportion that could contribute to

obstruction in labour (Konje and Ladipo, 2000). Obstructed labour is reportedly more common with girls that marry at an early age and because the reproductive capacity has not been fully developed, during the resultant childbirth fistula could occur (de Bernis, 2007, Melah, 2007, Wall, 2009).

There are contentions, however on the role of early marriage in fistula formation; in the systematic review of literature by the International Consultation on Vesico Vaginal Fistula, it was alleged that available reports on age and parity as potential risk factors, are controversial (Abrams, 2012). The study argued that poor access to emergency obstetric care appeared to be implicated, as women appear older in some of the reviewed studies (Abrams, 2010). In a recent a study in Uganda, Meurice et al (2017) reported women were older than 29 years. Heller and Hannig (2017) argued that early marriage does not usually mean 'early pregnancy' as, cultural restraints existing in some societies for sexual abstinence until girls are deemed "ready for sex, pregnancy and motherhood" (2017: 86). Any woman can develop the condition so long as the right predisposing obstetric factors converge namely 'large foetal size, mal-presentation, intervening disease or malnutrition'(Wall, 2006, Muleta et al., 2010), with poor access to healthcare as the major reported cause among fistula survivors for fistula formation (Gharoro and Abedi, 1999, Abrams, 2012, Phillips et al., 2016, Roka et al., 2013).

Other social causes of fistula are harmful traditional practices such as Female Genital Mutilation (FGM) (female circumcision) and/ Female Genital Cutting (FGC), that includes tearing of the soft tissue during difficult labour or obstetric procedures. The Hausa people of northern Nigeria, during difficult labour, hold the belief that 'gishiri', (a salt web) covering the vagina opening hinders birth. Hence a traditional health practitioner is consulted who creates series of incisions with a knife or blade to remove the obstruction (de Bernis, 2007, Melah, 2007, Wall, 2009, Ijaiya et al., 2010). A further issue that contributes to fistula is that of sexual violence such as rape (de Bernis, 2007, Longombe et al., 2008, Maheu-Giroux et al., 2015). In war torn countries, rape victims have been reported to develop fistula that can directly be related to injuries sustained during the sexual trauma (Longombe et al., 2008) or indirectly related such as, obstetric (obstructed labour) during delivery or as a result of iatrogenic causes, for instance

quacks performing evacuations after spontaneous abortion on pregnant women who were raped (Onsrud et al., 2008, Maheu-Giroux et al., 2015).

1.5.3 Consequences of Obstetric Fistula

The resultant hole between the bladder and vagina in VVF or the vagina and the rectum in RVF means a total loss of urinal and/or rectal control. Hence a constant flow of urine and or faeces from the bladder and or /rectum into the vagina, across the perineum down the legs (Wall, 2009). This causes physical irritation on the skin, and encrustments' on the vulva (Ahmed and Holtz, 2007, Wall, 2009). Additionally, infections and stone formations could occur in the bladder, vagina, urethra or ureter (Abrams, 2012). Other physical injuries such as pelvic related complications can also be a result of obstructed labour. This aspect is referred to as the "obstructed labour injury complex", and affects gynaecologic, gastrointestinal, urologic, musculoskeletal and neurologic systems (Arrowsmith et al, 2006: 9). Additional complications for women with fistula are foot drop, infertility, vaginal stenosis and chronic urinary tract infection (Ahmed and Holtz, 2007, Wall, 2012a). Table 1.2 presents some of the co morbidities in the 'obstructed labour injury complex':

Table 1.2: Field injuries/ comorbidities in obstetric fistula

Musculoskeletal	Footdrop
Neurologic	Saddle block
Dermatologic	Ulceration, skin infection
Renal	Renal failure, hydronephrosis
Gynaecologic	Amenorrhea, infertility
Systemic	Malnutrition, anaemia
Social	Homelessness, divorce, isolation
Psychological	Depression, suicide

Source: Abrams, 2012

Women with fistula have screened positively for mental health dysfunctions (Goh et al., 2005b, Zheng and Anderson, 2009). This could have resulted from the traumatic child birth, and/or the still birth experiences and the effect of the uncontrollable incontinence (Siddle et al., 2013). Psychological consequences include depression, feelings of worthlessness, anxiety, anger, and Post-delivery Traumatic Stress Disorder (PTSD) and suicidal tendencies or ideation (Kabir et al., 2003, Goh et al., 2005a, Ahmed and Holtz, 2007, Siddle et al., 2013). In addition, the attendant psychosocial disorders include self-isolation, stigmatisation, and loss of husband's affection, divorce and rejection by society, thereby compounding the physical, emotional and social trauma (Wall, 1998, Ahmed and Holtz, 2003, Mselle et al, 2011).

There are however contentions on the extent of stigmatisation and rejection women face. Some studies argue the majority of the women face extreme stigmatisation with high rates of divorce (Wall, 1998, Ahmed and Holtz, 2007), whilst other studies contend that there were women whose spouses and family continue to provide support (Bangser, 2007, Zheng and Anderson, 2009, Roush, 2009, Meurice et al., 2017). The condition is described to contribute to economic hardship for women and their families (Women's Dignity Project and EngenderHealth, 2006, Roush, 2009, Mselle and Kohi, 2015a), due to women's inability to work as they usually would have done in the past or family members having to provide financial support to seek for cure (Mselle and Kohi, 2015a).

1.5.4 Classification of Fistula

The location and nature of the fistula that develops is dependent on the point at which labour became obstructed and the amount of pressure the surrounding area received, the length of time the compression lasted and the tissues that were compressed (Wall, 2009). There is no standardised classification system for fistula. Various attempts have been made over the years to classify fistula but with opinions differing among the surgeons, there is presently no unified evidence based classifying system (Wall, 2006, Creanga et al., 2007, Arrowsmith, 2007, Goh et al., 2009, Karateke et al., 2010). The most commonly used system is the Waaldijk classification, which the International Consultation on Vesico Vaginal Fistula 2010 adopted as the classification system of fistula; based on the premise that Waaldijk is recognised to have documented large

number of cases from diagnosis to follow up (Abrams, 2012). Waaldijk classified fistulas into types I, II and III. Type II is further divided into A and B. Type III fistulas are those fistulas other than Vesico Vaginal Fistulas and comprises of recto-vaginal fistulas and uretero-vaginal fistulas (Waaldijk, 1995, Abrams, 2012). Incontinence deteriorates from type I through to II; in type I fistulas the closing device is intact. However, in type II fistulas increasingly more of the closing device is partially or completely lost as the classification type increases (Waaldijk, 1995). However, further research to validate Waaldijk classification and develop other classification was recommended by the International Consultation on Vesico Vaginal Fistula 2010 (Abrams, 2012). In a recent publication, another less technical classification was provided, simple fistula, complex fistula and intermediate fistula (Stamatakis et al., 2014). The simple fistulas are typically small in size (≤ 0.5 cm) and are there as solitary non- radiated fistulas. The complex fistulas include those fistula that have previously failed to be repaired or large-sized (≥ 2.5 cm) fistulas, mostly commonly a consequence of chronic diseases or radiotherapy (Stamatakis et al., 2014). The intermediate fistulas are those-sized between 0.5 and 2.5 cm, which some authors could classify as complex fistulas (Stamatakis et al., 2014, Malik et al., 2017).

1.5.5 Epidemiology of Obstetric Fistula

There are varying reports about the number of obstetric fistula in the population. The World Health Organisation suggested that there are 2 million women with untreated obstetric fistula in Sub-Saharan African and South East Asia (de Bernis, 2007), with an estimated 50,000- 100,000 new cases occurring yearly (Waaldijk, 1995, de Bernis, 2007). Another report suggested that in the case series of developing countries, 2% of cases of obstructed labour results into fistula (Dumont et al, 2001), hence based on the WHO's Global disease burden study that estimates that 6.5 million women develop obstructed labour, there would be 130, 000 new cases in these countries yearly (Wall, 2009). Published estimates of obstetric fistula incidence and prevalence has been criticised, that the method of calculation lacked scientific basis (Stanton, 2007, Abrams, 2012, Adler et al., 2013, Cowgill et al., 2015, Tunçalp et al., 2015). To address this, Adler et al's (2013) broadened search provided an improved estimation of over 1 million women with fistula, and with 6000 new cases developing yearly in Sub-Saharan Africa and south-

East Asia. The point prevalence, was 1.6 cases per 1000 women of the reproductive age (Adler et al., 2013). The review was limited to 19 studies as there was paucity of studies that used nationally representative sample or studies carried out in South east Asia (Adler et al., 2013, Tunçalp et al., 2015).

A recent review based on nationally representative surveys (DHS and Multiple Indicator Cluster Survey [MICS] data) from 19 countries in Sub Saharan Africa, estimated the lifetime prevalence to be 3.0 per 1000 women of reproductive age and a point prevalence of 1.0 per 1000 women of reproductive age. Based on this review, Ethiopia has the highest number of women currently living with the symptoms(110, 800) followed by Uganda (74,200), next is Kenya (49,900) and Nigeria is the fourth highest with an estimated 46,800 women (Maheu-Giroux et al., 2015). These figures are a far cry below earlier estimation that was in millions. However, the survey was limited to women 15-49 years living in the community who were available for the interview, excluding women already undergoing or awaiting treatment in health facilities, women in rehabilitation centres and women above 49 years (Maheu-Giroux et al., 2015, Ahmed and Tunçalp, 2015, Tunçalp et al., 2015). Again self-reporting as was employed in this survey, has a low diagnostic value for maternal complications (Ahmed and Tunçalp, 2015, Tunçalp et al., 2015). The relative rarity of obstetric fistula and the geographical remoteness where majority of cases occur means current estimates might still not be accurately representative (Ahmed and Tunçalp, 2015). Knowledge of the number is required for country specific effective policy development and planning for treatment and prevention(Ahmed and Tunçalp, 2015, Tunçalp et al., 2015). Hence there is still a need to develop better methods that combine facility and community surveys to provide good quality data to manage the burden placed by obstetric fistula (Ahmed and Tunçalp, 2015, Tunçalp et al., 2015).

1.5.6 Role of Health System in Obstetric Fistula Development

Obstetric fistula is usually used as a “marker of overall maternal health” in a country (Roush et al, 2012: 788) because the underlying socio-cultural factors that contribute to fistula formation are also responsible for most of maternal deaths and morbidities (Bangser, 2007, Roush et al., 2012). Several factors are responsible for the contribution

of health systems to the development of fistula in developing countries. The provision of essential obstetric care service is usually not adequate in most countries where obstetric fistula is prevalent. Many facilities lack adequately trained staff, materials and large number of patients they cannot cope with (Kirschner et al., 2010, Wall, 2012c, Phillips et al., 2016).

The lack of care and bad attitudes of hospital staff is another barrier to use of health facilities; harsh treatment by health workers has also been described to discourage seeking care in facilities (Ijaiya et al., 2010, Mselle et al., 2011a, Bohren et al., 2014). Women could arrive early and still not receive the required intervention (Mselle and Kohi, 2015b, Phillips et al., 2016). The presence of a SBA who would monitor the progress of labour using partographs and make timely referrals for EmOC is critical for fistula prevention (de Bernis, 2007, Capes et al., 2011, Abrams, 2012, Tebeu et al., 2012, Wall, 2012a). However, lack of proper monitoring during delivery for early detection of complication and management, and neglect by health workers was described (Wall, 2006, Ijaiya et al., 2010, Bangser et al., 2011, Mselle and Kohi, 2015b). Other issues highlighted were health practitioners showing favouritism and neglecting women who were not acquaintances or not willing to pay for favours (Mselle and Kohi, 2015b). In the extreme, in some studies there were allegations of torture by the women against the health workers (Bohren et al., 2014, Mselle and Kohi, 2015b).

The studies on women's experience during Ante Natal Care (ANC), describes the level of birth preparedness in forestalling complications that could lead to fistula. It has been reported that women are more likely to give birth with the aid of a skilled birth attendant if they had attended at least a single ANC (De Allegri et al., 2011, Anyait et al., 2012, Gudu and Addo, 2017). Poor attendance at ANC had also been observed to be a contributor to the development of obstetric fistula (Melah, 2007). ANC attendance for the index pregnancy that led to fistula, varied between attendance or one to four visits. The bad attitude of service providers towards rural women or those without history of ANC attendance was reported to dissuade some women from facility delivery (Velez et al., 2007). The case of non-attendance in the Niger study was to avoid stigma (Alio et al, 2011); women believed pregnancy was not a "disease", warranting treatment (Alio et al, 2011: 374). On the other hand, non-attendance of ANC by women in the Ethiopia

study was attributed to lack of awareness and access to services (Gebresilase, 2014). In study by Bangser et al (2011) where 84% of the women had at least two ANC attendances and 45% had four or more ANC attendances, women were not provided with guidance on birth preparedness (Bangser et al., 2011). Equally, in a five country study less than half of the cohort that attended ANC could remember being provided with information on dangers signs during delivery and birth plans (Landry et al., 2013). Women still delayed in seeking skilled birth care despite high ANC attendance in studies in Kenya and Uganda (Roka et al., 2013, Meurice et al., 2017). In Gudu and Addo's (2017) Ghanaian study, they assert the high uptake of ANC attendance was because of skilled health workers availability and quality of care received during the ANC. Hence, improving the skills of staff in delivering quality care during ANC could encourage utilisation of skilled birth care for delivery (Gudu and Addo, 2017).

The cost of obtaining care in facility has also been contributory to the development of fistula (Bangser et al., 2011, Mselle et al., 2011a), inability to afford hospital fees encourage women to patronize unskilled birth attendant like TBA that would accept payment in kind or in instalments (Jansen, 2006, Ijaiya et al., 2010, Tebeu et al., 2012). Seeking care entails payment of user fees and other 'out of pocket expenditure' that could include transportation costs, and paying for consumables such as sterile gloves, intravenous fluids (Jansen, 2006, de Bernis, 2007, Wall, 2009, Bohren et al., 2014). In recent years, health financing policies in developing countries has received attention with the aim of promoting equitable monetary healthcare access to the poor (Gabrysch and Campbell, 2009, Kyei-Nimakoh et al., 2017).

Limited household wealth presents a significant hindrance for service users across numerous sub-Saharan African countries (Say and Raine, 2007, Anyait et al., 2012, Amoako Johnson, 2016, Kyei-Nimakoh et al., 2017). Developing countries governments' increased participation in health financing such as user fee exemption is associated with skilled birth attendance utilisation and C- section (Kruk et al., 2007). However, in some countries where maternal health care services are free other indirect costs, for instance transport, may remain a significant obstacle for the less privileged (Anyait et al., 2012, De Allegri et al., 2015, Kyei-Nimakoh et al., 2017). In Ghana, even though on the national level the introduction of free maternal healthcare policy led to increased uptake of

skilled birth care, there were still regional inequalities where maternal educational, ANC and health services utilisation were known to be low, and poverty and fertility levels were high (Amoako Johnson, 2016). Thus, suggesting other non-financial obstacles related to quality of service for instance, long waiting period, providers' negative behaviour might serve as deterrent for women to seek skilled assistance for birth (Gabrysch and Campbell, 2009, Anyait et al., 2012, De Allegri et al., 2015).

To reduce financial barriers in accessing maternal health service, health insurance schemes provide incentives for women to seek facility care (Kuwawenaruwa et al., 2016, Wang et al., 2017). Health insurance is another avenue government finance health care access (Kruk et al., 2007). Health insurances have been poorly implemented; the coverage is low in developing countries with issues surrounding skewed coverage that favours the wealthy in urban areas (Wang et al., 2014, Wang et al., 2017). In Ghana and Kenya possession of health insurance coverage was positively associated with increased skilled care for births for wealthy women (Kitui et al., 2013, Amoakoh-Coleman et al., 2015, Gudu and Addo, 2017, Wang et al., 2017). In Tanzania despite the availability of insurance coverage, out of pocket expenses such as transport and past negative treatments by health workers are obstacles to maternal care (Kuwawenaruwa et al., 2016). In Ghana, health insurance services covers of out of pocket expenses (Enuameh et al., 2016) therefore pregnant women in rural areas with health insurance are likely to opt for skilled birth assistance in a health facility if available (Amoakoh-Coleman et al., 2015, Enuameh et al., 2016, Gudu and Addo, 2017). However, issues of poor uptake of health insurance, differences in interpretation of health insurance benefits serves as a hindrance to utilisation of maternal health service (Enuameh et al., 2016). Hence health insurance scheme even though a laudable approach in reducing inequality to maternal health care access, the design of the scheme requires improvement to achieve the required impact (Wang et al., 2014).

1.5.7 Prevention of Obstetric Fistula

The prevention of fistula using the public health approach can be achieved using the Haddon matrix (Abrams, 2012, Wall, 2012d). The Haddon matrix presents prevention on three levels; primary, secondary and tertiary. The primary prevention considers

addressing the indirect causes of fistula. These indirect causes which are referred to as the “root causes” of fistula include poverty, low social status, and long distance to health facility, high levels of illiteracy, and poor or absence of public-health education (Abrams, 2012: 46). At the primary level the effort is to eliminate or lower the risk of developing the condition. Secondary prevention on the other hand attempts to control the severity of the condition by stopping it at its initial stages(Abrams, 2012). Tertiary prevention aims to mitigate the complications of the condition(Abrams, 2012). See table 1.3 below

Table 1.3: Haddon matrix approach in preventing fistula

Factors					
	Objectives of intervention	International, national, regional	Community	Household	Hospital
Primary Pre-event	To identify risk factors associated with birth complications, mortality & VVF	Financial Aid Roads Education Communication Electricity supply Policy/Media Field surveys Medical staff training	Maternity insurance Marriage customs Prenatal care Midwife training Engagement and education of traditional birth attendants Community mobilised transport/ ambulance motor bikes Maternity waiting houses	Education of girls Delayed marriage ANC attendance Birth preparedness	Well-equipped facilities and trained staff

Secondary Event	Identifying/ addressing individual risk	Transportation Field Surveys	Maternity waiting houses	Seeking care early	Partographs Low gynaecological age, Grand multiparity Caesarean section, (Symphy- siotomy) Foley catheter drainage
Tertiary Post event	Treatment/ Re-integration	Media Campaigns	Microcredit/ Microenterp rise Acceptance/ support, absence of stigma	Support to seek cure early, support to reintegrate	Fistula surgery, rehabilitation program

Source: de Bernis 2006, Abrams, 2012

Primary Prevention Strategies

The primary aim at this level is to ensure that pregnancies are planned, prepared for and wanted and happens at the optimal time of a woman's life (de Bernis, 2007). Hence strategies are based on the health promotion and education for women, families and community; directed towards providing understanding on the importance of delaying age of first pregnancy, benefits of child spacing and improving access to family planning (de Bernis, 2007). It involves educating the community on the social, cultural and physiological factors that influence and increase the risk of fistula development (Miller et al., 2005, Banke-Thomas et al., 2012). Prevention also involves campaigns on special nutritional requirements of girls (Miller et al., 2005, Abrams, 2012) and the promotion of girl child education, as education is linked with improved economic status and improved infant survival on the family level (Miller et al., 2005, Abrams, 2012, Banke-Thomas et al., 2012).

Another key strategy is the Maternity Waiting Homes (MWH), this is to address the delays caused by distance, transport difficulties and terrain (WHO, 1996, Abrams, 2012). MWH are temporary shelters or houses close to health facilities where pregnant women can await the onset of labour (WHO, 1996, Abrams, 2012, Lori et al., 2013). They are notably of assistance for primigravidas and women who have been identified to have a great risk for complications of labour (WHO, 1996, Abrams, 2012). World Health Organisation endorsed MWH as part of the comprehensive package to reduce maternal deaths and morbidity (WHO, 1996). The MWHs serve as an access to timely skilled birth assistances by providing temporary accommodation near a health facility with health workers (Lori et al., 2013). However, a recent review by Penn-Kekana et al revealed that the implementation of MWH has faced maintenance and utilization challenges, hence recommended its operations should be organised within the health system with community involved in its planning and administration for success (Penn-Kekana et al., 2017).

Another primary prevention strategy that can reduce delay in seeking skilled birth care is through the provision of quality ANC and educating pregnant women on seeking timely delivery care at health facilities (Roka et al., 2013). The timely access to emergency obstetric care is also critical, families in the community can organise emergency transport plans (Miller et al., 2005). Improving the quality of care women receive during delivery has the potential to reduce the barriers to the utilization of skilled birth care (Bohren et al., 2014). Another primary prevention strategy is to engage the community. Community based groups working in partnership with community leaders can create awareness and advocacy to end harmful traditional practices, for instance Tostan in Senegal and Gambia mobilised the community to end FGM and forced child marriages, they also promote girl education (Miller et al., 2005).

A long-term strategy is developing national policies and strategies to prevent and treat fistula supported by media and the private sector (de Bernis, 2007). The factors that contribute to the development of fistula are the same that cause maternal and child mortality and morbidity, hence strategies for prevention and treatment should also be integrated into the wider national reproductive health, developmental and poverty reduction plans (de Bernis, 2007). The mobilization of international and individual

country political support is of critical importance for a successful eradication of obstetric fistula; this is because adequate resources can only be generated if maternal health is of high priority on national political agenda (Wall, 2012d). Individual countries need to put in a place an OF strategy committee to develop a national population specific strategy with measurable milestones (de Bernis, 2007). The OF strategy committee is responsible for mobilising support for the implementation of the primary, secondary and tertiary strategies.

Secondary Prevention Strategies

These are measures that include improving the healthcare system's response to improved access to emergency obstetric care, incorporating safe and timely intervention for women presenting with obstructed labour (Roka et al., 2013). It is essential to have trained health workers who can monitor each labour using a partograph; for early identification of woman at risk or who has developed obstructed labour for quick referral if emergency obstetric care (EmOC) services are not available on site (Wall, 2006, de Bernis, 2007). Emergency obstetric care (EmOC) "refers to care provided in health facilities to treat direct obstetric emergencies that cause the majority of maternal deaths during pregnancy, at delivery and during the postpartum period" (Paxton et al, 2006: 193). Facilities are designated as either basic or comprehensive EmOC. Basic EmOC facilities performs the following six functions, intravenous administration of antibiotics, oxytocic medicines and anticonvulsants, they also carry out manual removal of placenta and retained products and perform assisted vaginal delivery (Paxton et al., 2006). In addition to these functions, Comprehensive EmOC facilities provide the additional two functions of surgery (Caesarean section) and blood transfusion (Paxton et al., 2006) The provision of C- section at selected primary health care facilities whereby designated health centres are equipped with operating theatres and other surgical equipment can forestall the delay caused by referrals of cases to other health facilities (Roka et al., 2013). To improve patient care, staff motivation together with provision of management protocols and regular supply of materials would be required (Kayiga et al., 2016).

Tertiary prevention

The tertiary prevention strategy is the treatment and rehabilitation of women (Abrams, 2012). Early detection and diagnosis is important in order to prevent women developing fistula and returning home after surviving an obstructed labour (Abrams, 2012, Khisa et al., 2017b). Midwives and doctors can be trained in the use of indwelling urinary catheter to help prevent fistula formation or allow a small fistula to heal without repair in women who have survived an obstructed labour (de Bernis, 2007, Wall, 2009, Abrams, 2012). The establishment of competent fistula repair centres to carry out the tertiary prevention strategy for an established fistula is equally of critical importance. The development of fistula has physical, social, economic as well as psychological impacts upon the lives of affected women (Ahmed and Holtz, 2007, Gebresilase, 2014, Khisa et al., 2017c). Hence, addressing the need of women who have developed fistula to receive care and support goes beyond medical intervention (de Bernis, 2007, Wall and Arrowsmith, 2007, Donnelly et al., 2015, Assembly, 2016). A holistic care approach is recommended, facilities providing treatment should have the capacity to provide long term accommodation and rehabilitation using a multidisciplinary team for efficient team work (de Bernis, 2007, Mohammad, 2007).

1.5.8 Treatment of Obstetric Fistula

Treating a woman with an obstetric fistula can be complex. The main treatment is surgery performed under meticulous situations, success of which is dependent on good surgical skills, good nursing care and management of complications (Abrams, 2012). Sadly, the management of cases is hindered by the few qualified and dedicated fistula surgeons on the field (UNFPA and EngenderHealth, 2003, Abrams, 2012). There are also shortages of specialist nurses, physiotherapists, counsellors, social workers, occupational therapists and rehabilitation professionals (Abrams, 2012). Equally the major barriers women face in accessing treatments include lack of awareness of availability of treatment, facility shortages, and financial difficulties in paying for treatment and transportation difficulties (UNFPA and EngenderHealth, 2003, Bangser et al., 2011, Umoiyoho et al., 2011a, Abrams, 2012, Bellows et al., 2015, Baker et al., 2017). Other barriers not frequently cited were psychosocial namely depression and feelings of

anxiety and loss of self-worth, and cultural barriers which included lack of autonomy to seek care, negative conceptions about hospitals and preference for traditional medicine (Umoiyoho et al., 2011a, Abrams, 2012, Bellows et al., 2015, Baker et al., 2017). Women attributing the cause of obstetric fistula to evil spirit or God's curse or sin committed or even a sexual transmitted infection has also served as obstacle to seeking care (Women's Dignity Project and EngenderHealth, 2006, Abrams, 2012, Emma-Echiegu et al., 2014). Women who had attempted an unsuccessful repair at health facility were left frustrated by the necessity to undertake repeated visits and this created a barrier.

Mobilising the resources and navigating the barriers to obtain treatments was usually done with the assistance of family (Pope et al., 2011, Yeakey, 2011). The period of waiting and receiving treatment varies from region to region depending on awareness and availability of repair services; this can range from less than one year to six years (Wall et al., 2004, Mselle et al., 2012, Landry et al., 2013). Authors also report women living with fistula for over 20 years before receiving treatment (Women's Dignity Project and EngenderHealth, 2006, Pope et al., 2011).

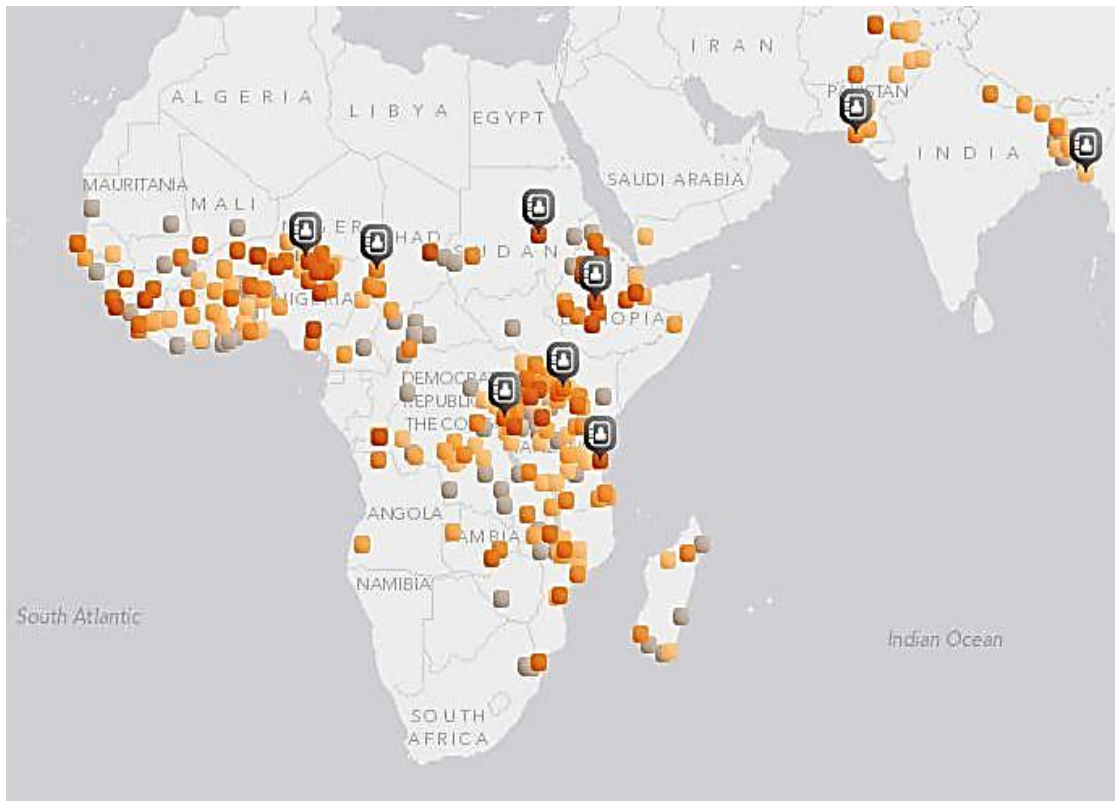


Figure 3: Global fistula Map showing fistula repair centres

Source: Direct Relief

The clinical goals of fistula repair surgery are primarily: (1) to close the fistula and (2) to make the woman continent and able to return to a normal and active life (de Bernis, 2007, Mohammad, 2007). The best outcome for fistula closure is for those that present early enough within three months after the injury; with quick initiation of prolonged bladder drainage by catheterization (Waldijk, 2004, Wall, 2006). The best fistula closure outcome is usually in the first attempt with prognosis for success decreasing with subsequent attempts (Waldijk, 2004, Wall, 2006, Karateke et al., 2010, Abrams, 2012). Two weeks or more of postoperative care is needed to ensure a successful outcome (Genadry et al., 2007, Abrams, 2012). However, closing the fistula will not always result in the return of urinary (and/or faecal) control. The presence of vaginal scarring appears to be an important prognostic factor in determining the chances of both successful fistula closure, and for the development of debilitating urinary stress incontinence (USI) after what could have been rated a successful fistula repair (Muleta, 2006, Wall, 2006, Abrams, 2012, Stamatakos et al., 2014). Furthermore, restoring continence remains a challenge, especially in a fistula where the urethra and/or bladder neck have been

destroyed (Waaldijk, 2004, Wall and Arrowsmith, 2007, Abrams, 2012, Stamatakis et al., 2014).

There appears to be difficulty in defining what qualifies as success in repair (Creanga and Genadry, 2007, Creanga et al., 2007, Wall and Arrowsmith, 2007, Goh et al., 2009, Kirschner et al., 2010, Hawkins et al., 2013). Generally success is defined by fistula closure by discharge based on tailored definitions and subjective outcome appraisal with no regards of the impact of the procedure on the quality of life (Genadry et al., 2007). Reported success rate of closure for simple fistulas are 70-95% and for complex cases 30% to 60%, and about 25-55% of women are estimated to remain incontinent after successful closure of the fistula (Wall, 2006, Creanga et al., 2007, Kirschner et al., 2010, Tayler-Smith et al., 2013, Malik et al., 2017). However for women, success is rather the return of continence control and not the surgeon's high closure rate data (Kirschner et al., 2010) and to resume normal living (Wall and Arrowsmith, 2007). For woman and people around her, persisting incontinence even after a successful closure of the fistula is a failure (Abrams, 2012). Furthermore, incontinence is just a single component of the spectrum of injuries as earlier identified in the 'obstructed labour injury complex'. The other overlooked complications of obstetric fistula formation and/or the complications of fistula repair are numerous, and they include the following:

- Recurrent Fistula
- Infections: wound, urinary tract infections (UTI) and pyelonephritis and urosepsis.
- Voiding Dysfunction (overactive bladder –incomplete micturition – Dysuria)
- Ureteric obstruction (ligation – fibrosis– injury)
- Outlet obstruction (meatal stenosis, urethra stricture, bladder neck obstruction [BNO])
- Bladder contracture
- Vaginal stenosis (overcorrection – fibrosis)

- Sexual dysfunction (vaginismus – dysparunia)
- Rare complications (granulomas – diverticulum formation)
- Neurological complications (foot drop – neurogenic bladder)
- Complex neuropathic bladder dysfunction and urethral sphincter incompetency often result, even if the fistula can be repaired successfully
- Psychological trauma (social isolation – divorce)

Management of the complications can be instituted before repair if it would impact negatively upon outcome or care can be provided post-surgery (Abrams, 2012). Counselling and support are also important to address emotional damage and facilitate social reintegration (Abrams, 2012). The closure of the fistula is a primary step in the long process of restoring the health of women and re-establishing lost social relationships that resulted from fistula formation (Wall and Arrowsmith, 2007, UNFPA, 2015). Success in fistula surgery therefore, according to Wall and Arrowsmith, should go beyond closing the “continence gap”, but must include improving future fertility by restoring normal sexual functions, healing the psychological traumas and successfully reintegrating them back into their community (2007:844). According to Donnelly et al (2015) in holistic care, in addition to surgery during post repair management care, vigorous counselling on fistula prevention and setting up follow-up system for identification should be done. Furthermore, the counselling should address needs on sexual and reproductive health, primary care and mental health issues. It should also provide income generation support and engage affected women, their family and communities in quality reintegration experience (Donnelly et al., 2015).

1.5.9 Social Reintegration of Treated Women

The root causes of the condition and the consequences of fistula formation have triggered the call for a comprehensive response to fistula beyond the restoration of physical and functional continence. It requires support to the multiple and interconnected physical, social and psychological issues that prevents coping with life and regaining self-worth after treatment (Ahmed and Holtz, 2007, Mohammad, 2007,

Barot, 2010, Abrams, 2012). Hence the increasing focus on the need for 'social reintegration' for women with fistula by various authors (Tafesse et al., 2006, Jones, 2007, Muleta et al., 2008, Esegbona, 2012, Drew et al., 2016, Jarvis et al., 2017). The inclusion of the word "social" in social reintegration is with reference to placing the emphasis on raising "social functioning" in mitigating the poverty background and the negative consequences of exclusion in returning to the social, economic and cultural fabrics of community living (Esegbona, 2012: 184). However, there is no unified definition of the social reintegration (UNFPA, 2009) and equally there is a paucity of robust evidence of impact of reintegration strategies on women after repair (Abrams, 2012). Esegbona (2012) defined social reintegration as:

"Appropriate interventions that help women with obstetric fistula overcome physical, psychological and socio-economic challenges, freely identified by them, in order to enhance their return to the communities and social networks of their choosing, such that the risk of them presenting with another fistula is minimized" (Esegbona, 2012: xxxiii).

The goal of social reintegration is to break the fistula recurrence/occurrence cycle in which the woman's physical state is inextricably linked to her psychological state and her socio-economic condition (Esegbona, 2012). Social reintegration should therefore begin from the time the incontinence becomes evident, and thereafter for every subsequent intervention the primary goal should be the reintegration of the woman, back into community (Esegbona, 2012). Therefore, social reintegration is the responsibility of everyone who cares for the woman.

Table 1.4: Social Reintegration Interventions

Element	Level		
	Facility	Political	Community
Physical Improved physical health	Early detection Rehabilitation Skilled surgeon Timely repair Designated space	Allocation of funds for treatment	Outreach Health education Follow up
Psychological Improved mental health	Psychosocial therapy (e.g. counselling) Peer support	Raise awareness on issues of stigmatization	Advocacy and sensitization Follow up
Socio-Economic Increased social connection	Vocational skill training Linkage with existing programmes	Link up with on-going national poverty alleviation programmes	Microcredit or finance Follow up NGO Community based

Source Abrams (2012) and Mohammed (2007)

The table 1.4 above, describes the social reintegration interventions that can be provided within the three elements of physical, psychological and socio-economic status, and what the facility treating the patient, the community and political commitments are required to do (Esegbona, 2012). Quicker access to repair is purported to contribute to successful reintegration (Pope et al., 2011). The quick closure minimises the period being viewed as abnormal by her spouse or community members, hence decreasing the chances of the devastating social consequences of divorce or stigma (Pope et al., 2011, Esegbona, 2012). However, fistula survivors' perspectives are required in determining what social reintegration is and what services are required to

meet their needs (UNFPA, 2009, Abrams, 2012, Esegbona, 2012). There is an absence of follow up of survivors in the continuum of care and the low unacceptable numbers receiving reintegration services despite the glaring need (Assembly, 2016, Abrams, 2012).

1.6 Study Setting- Nigeria

1.6.0 Country Brief; History, Geography and Economy

Nigeria is in the western region of Sub Saharan Africa. Nigeria became a nation in 1914, when the British rulers amalgamated the northern and south protectorates. In 1960, Nigeria gained her independence from Britain (NPC and ICF, 2014). Nigeria is reported to have the highest population in Africa with the 14th largest land mass and is the seventh most populated country in the world (NPC, 2007, NPC and ICF, 2014, PRB, 2017). In the last national census in 2006, the population was 140.9 million, with an annual growth rate of 2.9 – 3.3 per cent (NPC, 2007). In 2017 the mid-year population was placed at about 190. 9 million, this is projected to rise to 219.7 million by 2050 (PRB, 2017).

Administratively the country is made up of 36 states and a Federal Capital Territory (FCT) (figure 4), which are grouped into 6 geopolitical zones (North East, North West, North Central, South, South East and South West). There are 774 Local Government Areas (LGA). Nigeria is a highly multi ethnic and culturally diverse society, there are about 374 ethnic groups, with Igbo, Yoruba and Hausa as the three major ethnic groups (NPC and ICF, 2014). There are broad regional, socio-cultural, economic and geographical diversities across the country (FMoH, 2009).

Agriculture was the main economic source of revenue prior to discovery of oil in 1953. And over the years there was a gradual marginalization of agriculture in favour of petroleum products (Lasisi and Shodiya, 2017). Nigeria's current major source of revenue is crude oil; she is Africa's biggest exporter of crude oil, with the largest reserve of natural gas (NPC and ICF, 2014). Generally there is huge dichotomy between wealth and poverty, though rich in natural resources the economy cannot meet the basic need of the population, vast majority are poor - 71% living on less than a dollar per day and

92% living on less than two dollars a day (UNICEF, n.d). In the United Nations Human Development Index 2015, Nigeria ranks 151 out of 177 countries (UNDP, 2016).

There are massive regional disparities in socioeconomic effects in Nigeria, with the southern region of the country performing better than the northern region in numerous respects (WB, 2011). The disparities in wealth distribution are thus; the 43% of the population in highest wealth quintile are in urban area as against 5% in rural area. Regionally also, the population with highest quintile of wealth are in the south regions of the country, while those in the lowest quintile of wealth are mainly in the North - West and North-East of the country (NPC and ICF, 2014). In terms of education, there were gains recorded in promoting primary education through the Universal Basic Education policy, which was aimed at providing educational opportunities to children of primary school age with emphasis on promoting girl child education and opportunity for underserved children; for instance street and nomadic children (WB, 2011). However, despite these achievements, children in the south are still most likely to attend school than those in north. Furthermore while in the southern regions girls and boys attend school equally, in the north boys are still more likely to attend school than girls (WB, 2011, NPC and ICF, 2014, NPC, 2015).

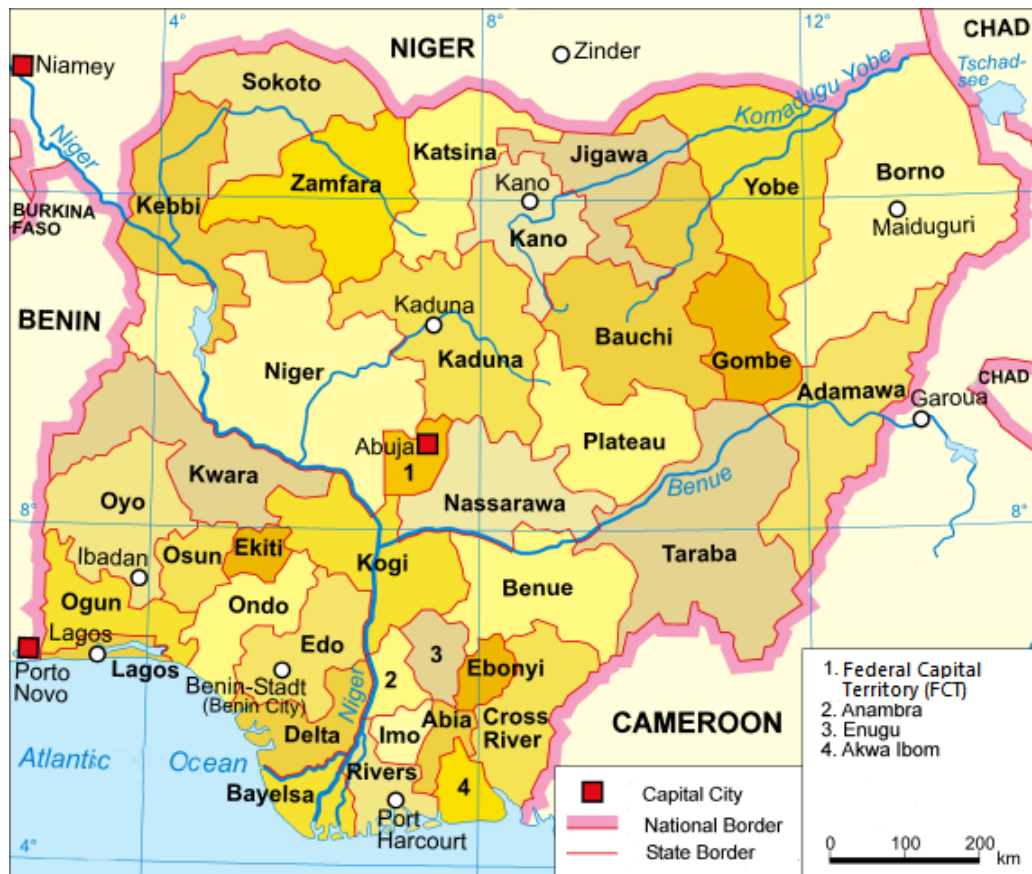


Figure 4: Map of Nigeria showing 36 states

1.6.1 Maternal Health and Development

Nigeria ranked 187th out of 191 countries in WHO overall health efficiency ranking (Tandon et al., 2000). Seventeen years down the line, maternal health of the population is still of major concern. Not enough progress was made towards meeting the MDG 5 target by 2015 (Mallick et al 2016); for instance Nigeria is listed among the six countries that account for half of the global under-five mortality (UNICEF et al., 2017). Nigeria with India accounts for one third of the global maternal mortality as earlier discussed (WHO, 2015). It is pertinent to note here that in 2013 before the expiration of Millennium Development Goals (MDGs), globally in maternal mortality, Nigeria(14%) ranked second after India(17%), but in the 2015 report, the reverse was the case (WHO, 2014, WHO et al., 2015).

The Maternal Mortality Ratio (MMR) as at 2015 was 814 per 100,000 live births (WHO et al., 2015). The national aggregated MMR figure masks the regional disparity in distribution of the mortality, for the northern region appears to be the major contributor to this high mortality. For instance in 2010 the MMR for North East Nigeria is 1,549 per 100,000 live births as against 165/100,000 live births in South West Nigeria (FMoH, 2015b, Izugbara et al., 2016). Studies further show that the worst maternal mortalities are in the rural areas in the northern region (Adamu et al., 2003, Doctor et al., 2012, Guerrier et al., 2013, Sharma et al., 2017). Table 1.5 below presents selected indicators of the health performance related to maternal health the subject of interest.

Table 1.5: Country maternal health related indicators

Total population 2017 mid-year (worldpopdata.org)	190.9 Million
Total Fertility rate (children per woman)	5.5
Crude Births Rate (per 1000)	39
Births per year (per 1000)	36.9
Maternal mortality ratio (per 100,000 live births) 2015	814
Proportion of births attended by SBA	38%
Proportion of births delivered in health facility	36%
Proportion of ANC (at least four visits)	51%

Source: Nigeria Demographic and Health Survey 2013

The health care delivery system is pluralistic; orthodox and traditional health delivery systems operate independently but alongside each other (FMoH, 2009). The orthodox health care system is organised into three levels; primary, secondary and tertiary

delivered by both the public and private sectors (FMoH, 2009, FMoH, 2016). The health work-force density is slightly above the African country average in WHO's global health work-force statistic, Nigeria has 2.52 health workers per 1,000 as against 2.3 (FMoH, 2016, Kress et al., 2016). There is however a mal-distribution; along rural- urban and geopolitical zones. The northern regions tend to have less health workers than the southern regions (FMoH, 2016), this has been made worse by the insurgency in the north in the past years that has crippled health services leading to catastrophic consequences on the health of the population, worsening the poor maternal health indices (Omole et al., 2015).

The administration of the public healthcare system is based on the three tiers of government that are federal, state and local. The Federal Ministry of Health (FMoH) provides the overall leadership, formulating national policies and providing some level of standardization, however each level is mostly autonomous in the financing and organisation of services under its authority (FMoH, 2009). The health system is characterised by broad regional variations in "status, service delivery, and resource availability" (NPC and ICF, 2014:5). Poor health service provision and delivery has been linked to inadequate health financing and poor governance (Kress et al., 2016, Adedoye et al., 2017). The constitution of the country unfortunately is not explicit on the roles of the three levels of government in the administration of health services, however in the National Health policy, primary health care (PHC) is the responsibility of the local government, secondary the state government and tertiary the federal government (FMoH, 2009, FMoH, 2016).

The PHC is the avenue for the provision of cost effective maternal and child services (Adeyi, 2016). The PHC which constitute the bedrock of the nation's healthcare system is managed majorly by the local government authorities that lacks political will, funding and capacity to perform (FMoH, 2009, Kress et al., 2016). At the federal level the National Primary Health Care Development Agency is responsible for the development and implementation of policies of primary health care services alongside the FMoH (FMoH, 2009, Kress et al., 2016). There are multiple parastatals involved in coordination of program implementation, and harmonisation of the activities between these parastatals is poor (FMoH, 2016, Kress et al., 2016). Hence, overlapping responsibilities,

which contributes to duplication of effort, wastage, or outright neglect (PRIMASYS, 2017, Kress et al., 2016, FMoH, 2016). Other challenges include frequent change in leadership, corruption, lack of accountability and transparency, and lack of harmonisation between the three levels of government in the coordination of activities (FMoH, 2009, FMoH, 2016, PRIMASYS, 2017).

The Nigerian government's expenditure as a per cent of total government expenditure is 8.2%. Meanwhile, African leaders at a special meeting in 2001 of the Organisation of African Union (OAU) in Abuja, Nigeria, recommended 15% of total national budget be allocated to health in view of the appalling situation of health care delivery caused by poor funding (FMoH, 2009). As at 2014, the government's total Health expenditure (THE) per capita was \$118, which is only 3.67% of the GDP. Nigerians mostly finance their healthcare with 'out of pocket payments' (OOP); the private out-of-pocket expenditure was 72% and general government health expenditure was 25% of the THE. The social security expenditure as a percentage of the government's general health expenditure was 0.0% while OOP as a percentage of private health expenditure was 95.7%. The disbursement of revenue occurs as unconditional transfers from the federal through the state and to the local government authority, each level has an independent expenditure autonomy (Kress et al., 2016). Financial and political constraints at the state level hampers funds transfer to local government, equally local governments lack internal revenue generating mechanism hence PHC functions are hindered (Kress et al., 2016). The low level of government funding translates into great reliance on user fees to fund health care, hence limiting the access to care for the poor (Kress et al., 2016, FMoH, 2009).

To address the problem of funding, various measures were put in place which includes National Health Insurance Scheme (NHIS) that incorporates programmes covering public sector workers, and the community-based health insurance (FMoH, 2009). Other measures include the social health protection models targeted at the poor and vulnerable groups for instance the free maternal and child health (MCH) services, voucher schemes, health cards and exemptions; and private health insurance (FMoH, 2009). In the NHIS scheme, the unemployed who constitute a large percentage of the population are excluded, hence access to health service is limited hence, the gap in

health inequality still remains (Onotai and Nwankwo, 2012). The community based Insurance scheme which targets the rural population and persons in informal sector is still in the developmental stage (Uzochukwu et al., 2015). As at 2016, less than 5% of the population is covered by any health insurance policy, only federal government workers are fully enrolled in the NHIS, and in many states public workers are not enrolled (FMOH, 2016, Adeloye et al., 2017). The free maternal health care has been implemented in some states on various levels. This could be the comprehensive package that includes all components of care (prevention, treatment and surgery) or partial free maternal care (Okonofua et al., 2011, Oyeyemi and Wynn, 2014, Uneke et al., 2014, Azubuike and Odagwe, 2015, Mallick et al., 2016).

Over the years in addressing the poor state of health, particularly maternal and child health, the government through the FMOH has developed and implemented policies and programs (FMOH, 2007, FMOH, 2009, FMOH, 2016, Mallick et al., 2016). A review revealed that there have been 34 policies, programs, and strategies directed at improving maternal, neonatal, and child health, developed between 1988 and 2014. These included 15 child, 9 neonatal, and 10 maternal health programs, including adoption of an integrated maternal, new-born and child health program (IMNCH) in 2007 (FMOH, 2007, Kana et al., 2015). The Midwife Service Scheme (MSS) program was initiated in 2009 to tackle the crisis of inadequate health workers as skilled birth attendants, especially in rural areas (Abimbola et al., 2012, Mallick et al., 2016). Newly graduated, unemployed, and retired midwives were engaged to temporarily work for one year in rural areas (Abimbola et al., 2012, FMOH, 2016, Okeke et al., 2017). The midwives were posted to selected primary care facilities with the capacity to provide basic EmOC and were linked to a secondary care facility with the capacity to provide comprehensive EmOC (Abimbola et al., 2012, Okeke et al., 2017). But sadly, the fragmentation and the bureaucracy within the federal, state and local government authorities affected the disbursement of funds and the coordination of activities (Abimbola et al., 2012, Okeke et al., 2017). Hence the MSS scheme did not lead to the desired outcome; the main gain within the first year was an improvement in ANC utilisation, however there was no evidence of improvement of skilled birth assistant or institutional deliveries (Okeke et al., 2017).

The disparity in the utilisation of maternal health still existed along geopolitical zones despite the MSS scheme (Abimbola et al., 2012, Okpani and Abimbola, 2016) . The disparity is linked to maternal education, household wealth quintile, place of residence (urban or rural), and geopolitical zone; women within most advantaged groups utilise ANC, skilled delivery assistance, and post-delivery care more (NPC and ICF, 2014, Mallick et al., 2016, Okeke et al., 2017). The challenges that contributed included shortage of, and inability to retain midwives due to, difficulties in relocating to new post, inadequate housing accommodation, irregular payment of salaries, and lack of training and opportunities for professional development. Other challenges were, in many cases the infrastructure in the health facilities remained poor, also there were issues around availability of drugs and supplies. Other barriers faced by women were transport and high user fee in paying delivery charges (Okpani and Abimbola, 2016, Okeke et al., 2017). Despite proven cost-effective interventions, programs, and policies to improve maternal health, maternal mortality and morbidity remains a public health challenge in Nigeria (Mallick et al., 2016).

1.7 Obstetric Fistula in Nigeria

1.7.0 Prevalence and Incidence of Fistula

There are conflicting reports on the estimated number of women living with fistula in Nigeria. An earlier report which has been disputed by various authors estimated there are about 800,000 women living with the condition (Wall, 2002). In the DHS (2008), the lifetime prevalence was placed at 0.4%, applying this to the number of women in the reproductive age (37,425,000) the number of women living with fistula or have experienced incontinence in the past was estimated to be 149,700 (NPC and ICF, 2009, FMoH, 2013).

In the 'National strategic framework for the elimination of obstetric fistula in Nigeria', the Federal Ministry of health stated that Nigeria accounts for 40% of the worldwide fistula prevalence with approximately 20,000 new cases occurring each year, although recent studies put estimates at approximately 12,000 new cases per year (FMoH, 2013). A recent study however, estimated Nigeria to have about 46,800 women living with

fistula making it the fourth highest globally (Maheu-Giroux et al., 2015). Sadly, the current DHS 2013, included no fistula-related questions and therefore the opportunities for generating prevalence estimates has been missed (Tunçalp et al., 2015). Meanwhile in the recent but yet to be published strategic framework for elimination of obstetric fistula 2018-2022, Nigeria's prevalence is placed at 15% of the global estimate (FMoH, 2018). This notwithstanding, the high MMR of 814 per 100,000 live births (the highest globally) is of worrisome concern, since maternal mortality is a fraction of maternal morbidities (Firoz et al, 2013).

1.7.1 Risk Factors for Obstetric Fistula Development in Nigeria

Obstetric fistula occurs in both the North and South regions of Nigeria, however according to the DHS (2008), the Northern region of the country has the highest prevalence of 0.5% as against 0.3% of the Southern region (NPC and ICF, 2009). The Northern region has been reported to have lower utilisation of maternal health services than the South (Galadanci et al., 2007, Mallick et al., 2016, NPC and ICF, 2009, NPC and ICF, 2014), hence might explain the higher prevalence of fistula in the Northern region. Studies have proposed that some of the aetiology differs according to the regions. Equally there are some commonalities in the aetiology.

- Socio-Cultural Factors

Generally the society is patriarchal, where the man plays the leading role and the gender role ideology places a woman's traditional role to be wife and a mother, while the man is in the public domain (Makama, 2013). Family relationship is hierarchical, and polygamy is practiced in some culture (Makinwa-Adebusoye, 2001, Makama, 2013, Aluko, 2015). This has been shaped by the influences of colonisation, urbanisation, Islamisation, and Christianity (Okome, 2003, Makama, 2013). The extent of women's subordination depends on what part of the country and it therefore varies along ethnic groups (Makinwa-Adebusoye, 2001). Women from the northern ethnic groups like the Hausa or Kanuri, have a lower status and lower level of decision making than women from Ibo, Yoruba and Ijaw ethnic groups from the southern region (Makinwa-Adebusoye, 2001). The Yoruba women even though in a patriarchal society are expected

to engage in income generating activities and therefore enjoy greater financial autonomy compared to other cultures or other women in other parts of the country that are not allowed or required to engage in such activities (Aluko, 2015). On the other hand, due to the influence of Islam, Hausa women are expected to be mothers and wives living a secluded life within the husband's compound, again respectability requires that their spouses control their reproductive capacity (Wall, 1998).

Child bearing plays a prominent role in all the cultures. In the Yoruba culture, like most of the other ethnic groups children validate marriage (Makinwa-Adebusoye, 2001). The Hausa bride is not regarded as a woman until she has given birth (Wall, 1998, Melah, 2007). Generally, women with children are conferred a special status that reflects their role in perpetuating the lineage, hence the desire for fertility (Wall, 1998, Ibisomi and Mudege, 2014). The Total Fertility Rate (TFR) in Nigeria is 5.5, but for women in rural areas this is 6.2 as against 4.7 for women in urban areas. Also the South East (4.7), South-South (4.3), and South-west (4.6), which are the more urbanised zones in the country have lower fertility rates than the three mostly rural northern zones the North West has the highest TFR(6.7), followed by the North East (6.3)(NPC and ICF, 2014).

Obstetric fistula is reported to be found more commonly with the Hausa/ Fulani, the major ethnic group in the Northern region (Wall et al., 2004, Melah, 2007). The factors pertinent to the Hausa and Fulani are cultural norms and beliefs that include early marriage and traditional birth practices (Wall, 1998). These practices include 'kunya' (meaning-shame) to encourage modesty during first pregnancy, with no discussion of pregnancy in action or conversation and during labour. Therefore, women avoid crying out in pain when labour begins or seeking care at ANC. Moreover, the preference for traditional birth attendants allows the kneeling posture for birthing, and the 'gishiri' cut to facilitate obstructed labour by traditional birth attendants (Wall, 1998, Melah, 2007, Ijaiya et al., 2010, Amodu et al., 2017). Consumption of too much sugar or salt is believed by the Hausa to cause 'gishiri' (salt) deposits thereby obstructing the vagina and blocking delivery (Wall, 1998, National Foundation on VVF (NFVVF), 2003, Kirschner et al, 2010). The incisions to remove the 'deposits' could be done during pregnancy or during labour (Wall, 1998, NFVVF, 2003). Gishiri cut is not female circumcision, but it is listed as female genital mutilation/cutting (FGM/C) because the debilitating effects of the incisions

include severe haemorrhage, sepsis, and injury to pelvic organs, like the bladder, urethra, bladder and vagina (Wall, 1998, NFVVF, 2003). Female circumcision is not practiced in the northern region, but in some parts of the southern region (Okeke et al., 2012). Even though female circumcision has been reported to contribute to fistula in other countries like Ethiopia and Sudan (Browning et al., 2010, Sharfi et al., 2013, Hamed et al., 2017), articles identified from the south of Nigeria did not list it as a risk factor. It could be the researchers did not investigate this during the course of their study. But in a national newspaper, the Medical Director of the National Obstetric Fistula Centre was reported to have said 85% of cases seen at the centre in South East Nigeria were FGM victims (Anioke, 2016).

Women in the North are mostly younger (mean age 15 years) and are primiparous, as against the South where mean ages range between 25- 34 years and women are multiparous (Gharoro and Abedi, 1999, Wall et al., 2004, Ezegwui and Nwogu-Ikojo, 2005, Melah, 2007, Umoiyoho et al., 2011a). Poverty appeared to be the common factor across the country and women usually come from rural communities (Murphy, 1981, Wall et al., 2004, Ezegwui and Nwogu-Ikojo, 2005, Melah, 2007, Emma-Echiegu et al., 2014, Nweke and Igwe, 2017), but as discussed earlier, recent studies are suggesting urban incidences occur (section 1.5.1). Additionally, women from the northern region had low educational background; women without any education and with primary education. But in the southern region, some women had secondary education (Wall, 1998, Melah, 2007, Ijaiya et al., 2010, Daru et al., 2011, Umoiyoho et al., 2011a, Emma-Echiegu et al., 2014). In the Southern region women's poor health seeking behaviour was attributed to their preference for unorthodox health facilities such as chemists, traditional healers, "spiritual churches" (Wall, 2009: 316), even after have a good ANC attendance (Ekanem et al., 2010, Umoiyoho et al., 2011a). In addition, for the southern region there was more evidence of fistula formation that were caused by instrumental deliveries, hysterectomy, C-section or in some cases cancers (Gharoro and Abedi, 1999, Ezegwui and Nwogu-Ikojo, 2005, Obi et al., 2008, Ekanem et al., 2010).

- *Physical/Environmental Factors*

Common to both regions are the poor access to health facilities that can provide EmOC. This could be because of financial difficulties, bad roads, and distance or transportation issues (Ijaiya et al., 2010, Phillips et al., 2016). Delay in receiving care can be due to lack of trained staff for proper monitoring and referral, bad attitude of staff, lack of equipment and medicines (Ijaiya et al., 2010, Phillips et al., 2016). Some fistula survivors alleged that their fistula was caused by professional negligence by health workers which could be: not being told about birth complications during ANC or despite seeking health care as soon as labour commenced, negligence in not performing the necessary action (Phillips et al., 2016).

The crisis within the health system as earlier highlighted has translated into a poor health force and poor health facilities (Adeloye et al., 2017). Frustrations over poor working conditions and poor remunerations has led to incessant strikes by health workers that has left public health facilities shut down for months (FMoH, 2016, Adeloye et al., 2017). Doctors are reportedly reluctant to work in rural locations due to absence of educational and social opportunities for their families (Phillips et al., 2016). The poor quality of health services has made some people lose confidence in the health care system (FMoH, 2016). Health care has to be sought in the private facilities that charge high prices or those that can afford it seek care outside the country (FMoH, 2016), further worsening the health inequities.

1.7.2 Treatment and Prevention Programs in Nigeria

- *Government Response/Effort*

The government in 2002 through the Federal Ministry of Health with the collaboration of development partners' recognised efforts to address fistula should be part of the integrated efforts to improve sexual and reproductive health (FMoH, 2013). This led to the inauguration of a VVF technical working group that developed the national strategic framework for eradication of Fistula in Nigeria [2005-2010] (FMoH, 2013). The framework was developed to provide a holistic approach to the implementation of the interventions across the continuum of care that includes, prevention, treatment,

rehabilitation and reintegration (FMoH, 2013). The emphasis was to shift from a medical approach in tackling fistula to a multi-disciplinary and multisectoral approach, because of the complexity surrounding fistula in Nigeria (FMoH, 2013). Within the implementing period, a standard operating procedure for fistula management for nurses and surgeons were developed, also trainings of surgeons and nurses were conducted on fistula management (FMoH, 2011, FMoH, 2013). An estimated 2,000 - 4,000 women were reported to have received repairs each year. Another gain during the period was the inclusion of fistula for the first time in the DHS [2008] (FMoH, 2013). Furthermore, the government in aiming to achieve the millennium development targets developed policies and activities already discussed above (section 1.6.1). Despite these efforts, obstetric fistula remained an issue of concern due to the declining quality of maternal health care services and increasing level of poverty (FMoH, 2013).

After the expiration of the first strategic framework in 2010, a situational analysis was undertaken and the National Strategic Framework for the Elimination of Fistula 2011-2015 was developed (FMoH, 2013). The focus of the framework was to align with National Strategic Health Development Framework that was developed in 2009, that aimed to improve the health systems and outcomes of the population particularly for the poor and most vulnerable (FMoH, 2009, FMoH, 2013). The overarching goal of the framework is “eliminate fistula related to childbirth through improvements in reproductive health outcomes of girls and women” (FMoH, 2013: 25). The targets were; reduce by 50% incidence of fistula, from current level increase by 50% treatment of fistula, increase by 50% reintegration for women in need of it and increase by 30% facilities providing rehabilitation services (FMoH, 2013). The elimination strategies were in three levels:

Primary Prevention

This was to be achieved through the creation of political, legal and social environments that promotes the improvement of women and girls status; issues to be addressed were gender equality, socio-cultural factors, and educating the girl child (FMoH, 2013). Additionally, laws and policies were to be reviewed that were deemed as obstacles to the utilisation of reproductive health services (FMoH, 2013). Pregnancy planning was to

be promoted through community mobilisation (FMoH, 2013). In addition, the community mobilisation was also to promote ANC, need for SBA and recognition of signs of complications during childbirth. Training of TBAs, and women were to be educated on ways of promoting safe delivery (FMoH, 2013). As part of this strategy, healthcare systems were to be strengthened to provide timely access to maternal care and emergency obstetric care by providing strategically located fully functional EmOC centres (FMoH, 2013).

Secondary Prevention

All SBA were to be trained to prevent fistula formation on small fistula, by early catheterisation for all women who had survived an obstructed labour at the facility level. Smaller facilities would provide prevention interventions that involve early diagnosis and management of fistula. And depending on the complexity of the fistula, repair would be carried out at higher level fistula centres (FMoH, 2013).

Tertiary Prevention

This was to restore hope and create the foundation for a new beginning. Intervention was to include psychological counselling, micro finance loans, skills acquisition, literacy classes, improving physical competence for a productive life after treatment and how to manage persisting incontinence for cases beyond repair (FMoH, 2013).

At the time of writing, the evaluation of progress that was conducted for the National Strategic Framework (2011-15) had been concluded and a new framework had been drafted. One of the major achievements noted in the report was the increased number of repairs within the reporting period with an purported reduction in prevalence of obstetric fistula (FMoH, 2018). The report is awaiting approval and pending circulation.

- Treatment and Repair Centres

Nigeria has 15 dedicated Fistula repair centres. Eight facilities are free standing repair centres with VVF repair operating theatres that have been donated by donor agencies like the UNFPA, UNDP, Fistula Foundation, Fistula Care Plus, Ford Foundation, Faith based organisations, and individuals. The others are part of a hospital and therefore share their theatre with other units. There are four National Fistula centres that serve

as national referral centre and one of these is Evangel Vesico Vaginal Fistula (EVVF) centre. The EVVF Centre is a designated a National Faith Based Fistula centre (EVVFC, 2017). These facilities are sponsored by donor agencies hence provide free surgical services. Treatment cost is borne by women when done in the non-designated repair centres such as tertiary or private health facilities. On the 22nd of August 2017, the Federal government issued a directive making fistula repair free at all teaching hospitals (Osakwe, 2017). The report stated that Fistula Care Plus project would co-sponsor treatments, while EngenderHealth would facilitate the training and retraining of surgeons and nurses providing care (Osakwe, 2017).

Despite the availability of treatment centres, the barriers that contributed to the development of fistula appeared to be the barriers to treatment (Wall, 1998, Warren et al., 2016). The two major barriers to care are, lack of awareness of availability of cure and poverty (Ekanem et al., 2010, Warren et al., 2016). Socio-cultural factors such as lack of awareness of the causes of fistula and women's low status that limits access to health care are barriers to seeking cure (Wall, 1998, Hassan and Ekele, 2009). Other barriers were availability of facilities with trained fistula surgeons to provide quality care, poor referral systems and transportation difficulties (Henry et al., 2012, FMOH, 2013, Tunçalp et al., 2014). Yet other barriers were the fear of embarrassment and stigma as a result of the incontinence (Ekanem et al., 2010, Warren et al., 2016).

1.7.3 Rehabilitation and Reintegration Program

There is a lack of scientific assessment of rehabilitation and reintegration programs in Nigeria (FMOH, 2013). Hence information provided in this section is mainly from organisational reports and government documents. Rehabilitations programs are currently provided at four locations, three of these are part of the treatment programs at two repair centres National Obstetric Fistula Centre (NOFC), Babbar Ruga, Katsina State; Jahun VVF centre, and EVVF centre, Jos), the fourth is at Kwalli rehabilitation centre Kano, coordinated by the state government. A Nongovernmental organisation, 'Women's Health and Development' a Foundation for Women's Health Research and Development (FORWARD) project funded by the UK's Department for International Development (DFID) from 1999-2008; this project provided treatment and rehabilitation

services. FORWARD received support also from the government through the National Program on Eradication of Poverty (NAPEP), the state's Ministries of Women Affairs and Agriculture (UNFPA and EngenderHealth, 2003). The repairs for FORWARD were carried out in a general hospital adjacent to the rehabilitation centre located in Dambatta, Nigeria (Mohammad, 2007). Nevertheless, currently there is no activity on-going in the FORWARD project (Lengmang, 2017, personal communication) and even activities at NOFC Babban Ruga cannot be confirmed. Efforts to trace the organisation proved abortive (phone calls and emails). FORWARD UK had no current information, instead provided details of an NGO coordinating FGM in the south of the country.

Rehabilitation programs are usually residential, women are accommodated within a hostel facility with meals provided (Mohammad, 2007, EVVFC, 2017, NOFC, 2017). The program is made up of physical and psychological rehabilitation. The psychological rehabilitation involves counselling sessions by trained counsellors and peers. The physical rehabilitation on the other hand, is in form of training that could include literacy and numeracy skills, and skills acquisition for income generating activities (Mohammad, 2007, EVVFC, 2017, NOFC, 2017). The income-generating skills varied with each centre; and could include sewing and knitting, cap- and soap-making, tie and dye, baking, bead making, groundnut oil production and animal husbandry (Esegbona, 2012, EVVFC, 2017, NOFC, 2017). FORWARD provided training on business management skills (Mohammad, 2007). Sometimes women are provided interest free micro loan or seed grants for business start-up (Mohammad, 2007, EVVFC, 2017). Period of training varied with the centre; at NOFC Babbar Ruga, training was for 9 months, at FORWARD's, an average of 10 months (Mohammad, 2007, NOFC, 2017), while the period of training for EVVF Centre was not stated. Graduation ceremonies are carried out upon completion of training and the ceremonies have been used as platform of community sensitisation (Mohammad, 2007, EVVFC, 2017). Rehabilitation also provided opportunity for physical recuperation necessary after surgery that could help prevent repair breakdown that were sometimes experienced (Esegbona, 2012).

FORWARD and EVVF Centre reported carrying out reintegration activities. FORWARD's reintegration activities include link up with community, through family counselling, meeting with local leaders and political for advocacy and sensitisation on reproductive

health and ease of reintegration of treated women into the community (Mohammad, 2007, Esegbona, 2012). Furthermore, FORWARD and EVVF centre organised follow up visits to communities to ensure successful reintegration (Mohammad, 2007, EVVFC, 2017). FORWARD reported that due to the physical, psychological and economic empowerment received during the rehabilitation, women were found to have an elevated status upon return in their communities (Mohammad, 2007).

A report of an evaluation exercise of rehabilitation services on two sites in 2008 suggested that government owned fistula rehabilitation programs follow a predetermined pattern which may not equip women with the necessary skills useful for their environment (Sambo, 2008). Hence there was a need to determine innovative but needs - tailored program in future interventions for effective social reintegration (Sambo, 2008). This observation was similarly reported in a recent study in Ghana, where fistula survivors found their acquired skills were inappropriate for the rural community market (Jarvis et al., 2017). Women in the Ghana study valued the opportunity to receive training but recognised the crucial part in determining what skills will provide practical products after repair (Jarvis et al., 2017). This observation appears to be relevant to the current on goings in rehabilitation programs in facilities in Nigeria.

1.7.4 Community Participation and Social Reintegration

Community involvement in the reintegration process is very crucial for its success. The gains of holistic approach of providing surgical repair together with social and psychological rehabilitation can only be achieved through community participation (Esegbona, 2012, Warren et al., 2016). Community awareness on causes of fistula and the need for skilled birth care during child delivery can potentially lead to reduced stigma against the condition. Additionally, it can lead to a change in health seeking behaviour for access to skilled birth care and treatment for fistula (Pope et al., 2011).

Early access to repair is advocated for, since it has been demonstrated that first attempts are usually the most successful and the longer it takes to get a cure the higher the chances of family disruptions (Melah, 2007, Umoiyoho et al., 2011a). Early access also minimises the period of which a women is viewed as abnormal by her spouse or community thereby contributing to successful reintegration (Murphy, 1981, Esegbona,

2012). This is of particular importance in the cultures where first child delivery is in the parents' home like the Hausa (Wall, 1998), and so recovery should have been completed by the time she is expected to return to her spouse's community. In line with this, EVVF Centre has adopted the early closure policy, where surgery is provided as soon as possible mostly within weeks of registering at the clinic after all due investigations have been carried out (Lengmang, 2016). Overcoming the barriers faced in receiving treatment particularly in remote rural areas would require improving on current awareness strategies beyond media announcements; to religious structures that play key roles in social interactions and support networks of women in Nigeria (Warren et al., 2016).

Community involvement is required in addressing the social marginalisation that can hinder successful reintegration (Esegbona, 2012). At the community level, the ability to return to, or secure a job, the reactions of spouse, family members, neighbours and community members can affect the reintegration after repair (Warren et al., 2016). Health workers and community leaders can conduct village meetings to educate the community on ways to discourage stigmatisation of treated women in the community and which can also serve as a forum to address cultural belief systems concerning the causes of fistula to improve care seeking behaviour (Emma-Echiegu et al., 2014). FORWARD trained fistula survivors to serve as community advocate supporting women living with fistula and educating community members on maternal health care (Mohammad, 2007). In Kankara and Nassarawa, community level interventions that were facilitated by community advocates provided the platform to address culturally sensitive issues relating to maternal health and fistula with community gate keepers, families, groups and community members (Sambo, 2008). Religious leaders play a significant influential roles in the community, hence can assist in proactive efforts through educating and encouraging their congregation on support for women with fistula (Warren et al., 2016).

1.8 Conclusion of Chapter

The chapter provided the background information on the study. An overview of how the thesis is structured and the motivation for the study was discussed in the first section of

the introduction to study. The second section was the research context, in this section maternal health issues in developing countries with a special focus on obstetric fistula in sub-Saharan Africa was discussed. Nigeria's history as it pertains to maternal health issues with greater emphasis on obstetric fistula development were also discussed in this chapter. The next chapter discusses the findings of the systematic literature review.

CHAPTER TWO

LITERATURE REVIEW

2. 0 Introduction to Chapter

This chapter presents the literature review on the experiences of women with obstetric fistula. A systematic search of the literature on electronic databases was carried out using defined selection criteria. Articles selected were initially appraised for methodological quality. Data extracted were synthesised using a thematic analysis framework. The discussions on the findings were thematically presented under the headings, *challenges of living with fistula; treatment and care experiences* and *reintegration experiences*. The research gaps are identified and used to derive the research question and objectives for the study.

2.1 Method

2.1.1 Information Sources

Relevant studies were identified by searching the electronic databases of, EBSCO host (MEDLINE, Academic Search Premier, PsychINFO, and CINAHL), POPLINE, Web of Science, Bioline International, Science Direct, and African Journal Online. Also, searches were conducted in the websites of World Health Organization (WHO), United Nations Population Fund (UNFPA), International Federation of Obstetrics and Gynaecology (FIGO), UK Department for International Development (DFID), United States Agency for International Development (USAID) Women's Dignity Project, Fistula Foundation worldwide and Engender health websites. In addition, Grey literature such as conference proceedings, thesis and dissertations using PROQUEST, official publications (such as Demographic Health Surveys) and technical or research reports by government agencies were searched.

Efforts were made to contact some clinical experts in obstetric fistula and principal investigators in studies identified for further clarifications. Eight corresponding authors were contacted via email and five replied providing clarifications. Hand searching of

references of articles selected was carried out to locate other articles that could be included. Systematic review articles that were selected were used to inform the search; articles used by the reviewers were cross checked if they met the selection criteria and the primary articles were retrieved for inclusion in selected articles.

2.1.2 Search Strategy

The following search terms were used to search all the databases: obstetric fistula, Vesico vaginal fistula, urogenital fistula, lived experiences, experiences, characteristics, psychosocial support, social support system, reintegration, rehabilitation and quality of life. Depending on its applicability on the different electronic database, the following strategies were employed:

- The key words were combined using the Boolean operators of AND OR.
- Truncation and wild cards symbols (* , ?)
- Years considered were from 2004 to present
- Time schedule: search was done each day from December 2014 to Mid-January 2015. Email alerts were set up on the electronic database websites for updates on new publications as the research work progressed. Evaluation and synthesis was carried out from mid-January 2015 till ending of February 2015.

2.1.3 Selection of articles

This was based on the following:

Inclusion Criteria

- Description of women's personal fistula life experiences
- Empirical research only
- Description of quality of life after treatment for fistula

Exclusion Criteria

- Clinical management procedures

- Surgical outcomes only
- Demographic characteristics only
- Risk factors for fistula development only
- Non- English papers
- Clinical classifications of fistula
- Non- empirical papers
- Descriptions of single medical conditions

2.1.4 Relevance and Coverage

Relevance was ascertained by reading through the contents, abstract or summary or the synopsis. Further confirmation was made by skim reading or scanning the document to see if it meets the criteria under review; to ascertain that it provided a description of lives and experiences of women with obstetric fistula and life after treatment.

2.1.5 Search Record

The search recording was documented- recording the following;

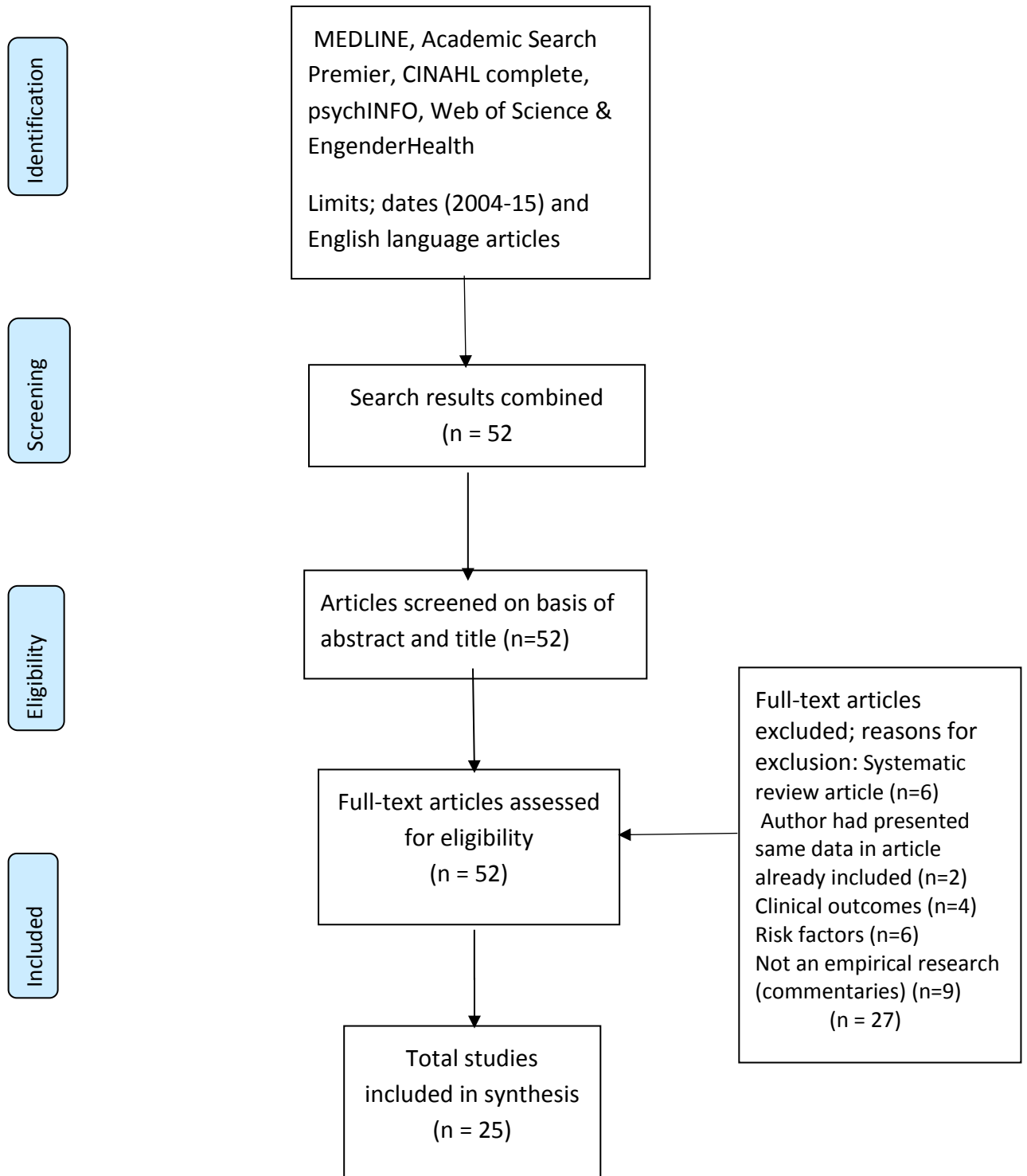
- The search terms used
- Source (the name of the database or index used)
- Date on which the search was run (or edited)
- Numbers of results
- Relevance of results
- Notes for future searches
- Numbering of each search for ease

2.1.6 Data Collection Process

The initial search yielded 1,194 articles for the databases of EBSCO (Academic search premier, CINAHL, PsychoInfo and Medline). With the removal of duplicates, 900 articles were screened using the title and abstract for inclusion. A total of 851 articles were excluded, and 49 articles were selected. Most of the excluded articles were on clinical repair procedures, case reports, prevalence surveys, classifications of fistulas, clinical symptoms assessments, surgical and management outcomes, socio-demographic characteristics of women with fistula and risk factors that contribute to fistula development.

The same search strategy was applied in the other databases of POPLINE, Web of Science, Science Direct, SCOPUS, Bioline International and African Journal Online. The databases of POPLINE, Web of Science, Science Direct and SCOPUS yielded articles already identified in EBSCO host databases. However, one additional article was identified from Web of Science. From the organizational database of EngenderHealth, only two articles were found eligible for inclusion. Altogether therefore, a total of 52 were selected as relevant. Reading through, 27 articles had to be excluded on the following basis: six were systematic review articles; two articles, the authors had presented same data in articles already included; six articles were on risks factors; 9 articles were found to be non-empirical research (commentaries); while four articles were on clinical outcomes. Below is the procedure used for the selection, presented in Figure 5, a flow diagram based on a modified PRISMA flow diagram (Moher et al., 2009).

2.1.7 Search selection process



Adapted from PRISMA flow diagram Moher et al (2009)

Figure 5. Flow Diagram of Search Selection Process

2. 2 Results

Table 2. 1 : Articles retrieved from systematic search

Author, Year and country	Title of article
1. Alio, A.P., Merrell, L., Roxburgh, K. et al., 2011. Niger	The psychosocial impact of Vesicovaginal fistula in Niger
2. Bangser, M. 2007. Tanzania & Uganda	Strengthening public health priority-setting through research on fistula, maternal health, and health inequities
3. Browning, A. and Menber, B. 2008. Ethiopia	Women with obstetric fistula in Ethiopia: a 6-month follow up after surgical treatment
4. Dolan, L.M., Dixon, W.E. and Hilton, P. 2008. United Kingdom	Urinary symptoms and quality of life in women following urogenital fistula repair: a long term follow up study
5. Donnelly, K., Oliveras, E., Yewondwossen, T. et al. 2015. Ethiopia	Quality of life of Ethiopian women after fistula repair: implications on rehabilitation and social reintegration policy and programming
6. El-Gazzaz, G., Hull, T.L., Mignanelli, E., Jeffery, H., Gurland, B. and Zutshi, M. 2010. USA	Obstetric and crypto glandular rectovaginal fistulas: long term surgical outcome; quality of life; and sexual function
7. EngenderHealth. 2012. Bangladesh and Democratic Republic of Congo	Living with obstetric fistula: Qualitative research findings from Bangladesh and Democratic Republic of Congo
8. Farid, F.N., Azhar, M., Samnani, S.S., Naz, A., Bohar, F., Syed, S., and Syed, S. 2013. Pakistan	Psychosocial experiences of women with Vesicovaginal fistula: a qualitative approach
9. Gebresilase, Y.T. 2014. Ethiopia	A qualitative study of the experience of obstetric fistula survivors in Addis Ababa, Ethiopia
10. Gharoro, E.P. and Agholor, K.N. 2009. Nigeria	Aspects of psychosocial problems of patients with Vesicovaginal fistula

11. Khisa, A.M. and Nyamongo. I.K. 2012. Kenya	Still living with fistula: an exploratory study of the experience of women with obstetric fistula following corrective surgery in West Pokot, Kenya
12. Landry, E., Frajzyngier, V., Ruminjo.J. et al., 2013. Bangladesh, Guinea, Niger, Nigeria, Uganda	Profiles and experiences of women undergoing genital fistula repair: Findings from five countries
13. Mohammed, R.H. 2007. Nigeria	A Community Program for Women's health and Development: Implications for the long-term care of Women with fistulas
14. Mselle, L.T., Evjen-Olsen, B., Moland, K.M. et al. 2012. Tanzania	"Hoping for normal life again": reintegration after fistula repair in rural Tanzania
15. Muleta, M., Hamlin, E.C., Fantahun, M. and Kennedy, R.C. 2008. Ethiopia	Health and social problems encountered by treated and untreated obstetric fistula patients in rural Ethiopia
16. Mwini-Nyaledzigbor, P.P., Agana. A.A. and Pilkington, F.B. 2013. Ghana	The lived experiences of Ghanaian women with obstetric fistula
17. Pope, R., Bangser, M. And Requejo, J.H. 2011. Tanzania	Restoring dignity: social reintegration after obstetric fistula repair in Ukerewe, Tanzania
18. Nathan, L.M., Rochat, C.H. and Grigorescu, B. 2009. Benin	Obstetric fistula in West Africa: patient perspectives
19. Nielsen, H.S., Lindeberg, L., Nygaard, U. et al. 2009. Ethiopia	A community based long term follow up of women undergoing obstetric fistula in rural Ethiopia
20. Siddle, K., Mwambingu, S., Malinga, T. and Fiander, A. 2012. Tanzania	Psychosocial impact of obstetric fistula in women presenting for surgical care in Tanzania
21. Turan, J.M., Johnson, K. and Polan, M.K. 2007. Eritrea	Experiences of women seeking medical care for obstetric fistula in Eritrea: implications for prevention, treatment, and social reintegration

22. Umoiyoho, A.J., Inyang-Etoh, E.C., Abah, G.M., Abasiattai, A.M. and Akasio, O.E. 2011. Nigeria	Quality of life following successful repair of Vesicovaginal fistula in Nigeria
23. Velez, A., Ramsey, K., and Tell, K. 2007. Bangladesh, Burkina Faso, Cameroon, CAR, DRC, Equatorial Guinea, Eritrea, Kenya, Malawi, Mali, Mauritania, Nigeria, Somalia, Tanzania, Uganda, Zambia	The campaign to end fistula: what have we learned? findings of facility and community needs assessments
24. Women's Dignity project and EngenderHealth. 2006; Tanzania	Risk and resilience: obstetric fistula in Tanzania
25. Yeakey, M.P., Chipeta, E., Rijken, Y. et al. 2011. Malawi	Experiences with fistula repair surgery among women and families in Malawi

Table 2. 2: Thematic Analysis Description of Experiences of Women with Obstetric Fistula

Author and year of study	Aims	Research design/ method	Data collection	Tests and analysis	Summary of findings	Limitations	Themes
Alio et al. 2011	Understand psychosocial effect of Vesicovaginal fistula	Qualitative; ethnographic method 21 women recruited from the Centre for reproductive health for maternity	In-depth interviews using different native languages with translators, for 2 hours average, over 2 days. Notes and audio recording was done	Coding based on ethnographic inductive approach and ecological model Themes generated from transcribed notes and interviews; verification of categories by team	Mainly rural dwellers, no formal education and married young None had prenatal care due to cultural stigma associated with it, all had long labour that began at home All described loss of place in society and social support Felt relieved on arrival for treatment to their peers; joy on full recovery of control Had positive plans for future	- Choice of research design not justified - Small sample size - Time of follow up not stated - Life experience after recovery sketchy; limited only to happiness and sense of self-worth, dignity	- Challenges of living with fistula

<p>Bangser. 2007</p>	<p>Studying the determinants of fistula to direct public health interventions</p>	<p>Qualitative and quantitative of four projects</p> <p>Study 1; purposive, 142 girls and women, family members, community and health workers</p> <p>Study 2; all hospitals in Tanzania, 161 selected, 85% responded</p> <p>Study 3; women, health workers and traditional birth attendants, sample size not stated</p> <p>Study 4; secondary data sources, DHS, Tanzania, 2004-5, Reproductive and child health survey, 1999, population and Housing census, 2002; Household budget survey, Tanzania, 2001</p>	<p>Study 1; in-depth interviews, discussions, and problem trees</p> <p>Study 2; 1-page survey questionnaire</p> <p>Study 3; semi-structured interviews, group discussions and case studies</p> <p>Study 4; data analysis</p>	<p>Not described</p>	<p>Study 1; most of participants not adolescent at time of occurrence of fistula; family provided support to majority of the women and girls; once healed, reintegration is complete</p> <p>Study 2; huge gaps in fistula repair services across country</p> <p>Study 3; due to distance, cost and other reasons that hinder care, women have to deliver at home</p> <p>Study 4; health outcomes worst with poor mainly with reproductive and maternal health. Rich utilize maternal health services better</p>	<p>-Details of the research not discussed; research design justification, details of data collection and analysis not provided,</p>	<p>- Challenges of living with fistula</p>
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<p>Browning & Menber. 2008</p>	<p>To enumerate outcomes of repair and quality of life, six months post-surgery</p>	<p>Quantitative All patient on discharge provided follow-up card and transport fee; 390 women, 240 returned for follow up</p>	<p>Structure interview in native language using standardised questionnaire</p>	<p>Interviews translated into English, entered in excel sheets. ten-point Likert scale used to grade impact</p>	<p>61.5% of women returned for follow-up. Women had varying grade of incontinence; some incontinence improved, some symptom free & some breakdown of repair One third had resumed sexual activity, 90% without pain 82.9% report improved quality of life, one woman reported worse</p>	<p>-No detail of ethical considerations for participants -Incentives (transport & additional expenses) provided for follow up visit -choice of research design not justified - loss to follow up from original study group 38.5% -follow up group majorly women not totally cured at discharge -details of data analysis not provided</p>	<p>-Reintegration experiences of women after fistula repair</p>
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						<ul style="list-style-type: none"> -Due to setting, women might have provided answers to please providers -Tools used not validated - follow-up period of 6 months not adequate to assess social changes 	
Dolan et al. 2008	<ul style="list-style-type: none"> -Examine long term lower urinary tract symptoms incidence -Establish onset time of symptoms with regards to repair 	<p>Quantitative</p> <p>All eligible women within cohort of treatment of 1993-2002; 35 contacted, 31 returned completed questionnaire</p>	<p>Questionnaire sent via post to respondents' minimum of 6 months post repair. Using self-administered questionnaire.</p> <p>Other information was obtained from</p>	<p>Questionnaire coded for recognition. Statistical analysis was by Mann-Whitney U test for continuous variables and Fisher's exact test for categorical variables</p>	<p>Women report varying degree of urinary symptoms. Majority, 87% reported symptoms did not impair lives.</p> <p>Sexual activities:</p> <p>vaginal dryness - 46%</p> <p>dyspareunia- 36%</p>	<ul style="list-style-type: none"> -Recall bias -Symptoms reported might not all be fistula or repair related -Small sample size 	<ul style="list-style-type: none"> - Reintegration experiences of women after fistula repair

	-Study urinary symptoms effects on quality of life and linkages between abnormality before repair, fistula site and symptoms after repair		patient's medical records		urinary symptom disturbed sex- 41%		
Donnelly et al. 2015	Study experience post repair and views about resuming healthy and valuable life	Qualitative; Purposive sampling of 51 women	-Community based in depth interviews in Ethiopian language, three to six interviews each day for 1.5 hours Notes and audio taping. Notes transcribed and translated into English	By narrative thematic analysis based on grounded theory; classification of domains followed by subtheme development and selection of quotes; team work on synthesising and revising themes. Feedback and clarification provided	Majority of women, uneducated; all fistulas develop after prolonged labour; high prevalence of stillbirths and first pregnancy. Women lived with fistula average of 9.8 years. After repair, great improvement in health but with some minor issues Improvement in psychological health with ability to resume normal life. But some still had reservations. Before repair, some had been divorced; but after	-Choice of research design not justified -Setting not justified -Sampling might have missed some women; only women with positive outcome selected - Language barrier	- Reintegration experiences of women after fistula repair

					<p>repair some women were redefining their marital status.</p> <p>Women now aware of delivery in facility;</p> <p>high desire to have children, but afraid of sex for fear of fistula recurring</p> <p>Few had children, others used contraceptive.</p> <p>Strong desire to be self-sufficient after recovery</p>		
El-Gazzaz et al; 2010	<p>-Investigate success rate of repair</p> <p>-Assess impact of repair on the long term on quality of life, sexual capacity and faecal continence</p>	<p>Quantitative</p> <p>All women (268) who had repair between June 1997-2009 were identified, 100 were contacted via telephone and consented</p>	<p>Via telephone, four question phone texts were administered. Thereafter validated questionnaire was posted to the women</p> <p>Data was also collected from IRB data base and patients records</p>	<p>Logistic regression, univariable and multivariable models used</p>	<p>Faecal incontinence had improved significantly post repair for women with obstetric related RVF</p> <p>No significant difference between QOL for both fistulas in either healed or not healed groups, also there were no significant differences in their sexual functions.</p>	<p>-Retrospective design</p> <p>-Small sample size for QOL Sexual function tests.</p>	<p>-Reintegration experiences of women after fistula repair</p>

EngenderHealth. 2012	To investigate the social and physical consequences of living with fistula and care seeking attempts	Qualitative Bangladesh: 4 women identified through household screening DRC: 33 women; at three sites	Interviews (key informant & in-depth open ended) & narrative history with women with fistula Focus group discussion- with women with fistula, women relatives, community members & men group	Not provided	Bangladesh: Coping mechanisms- changing and washing, restricting fluid intake, reduce prayer frequency, not going out to socialize Physical effects- genital rashes, burning, itch; anxiety, loss of self-worth Care seeking attempts- several & medicine shops, traditional remedies Social effects- divorce, rejection; insults from community members DRC: Coping mechanism- changing & washing, plastic covers, powder, perfume use Physical effects- genital rashes & sores, loss of	-Details of data analysis not stated -Data for another participant interviewed in Bangladesh not provided	-Challenges of living with fistula -Treatment and care experiences
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					<p>sexual desire, fatigue, dyspareunia</p> <p>Care seeking attempts-several, traditional and religious healers; barriers-distance, lack of support</p> <p>Social effects-separation. Divorce, rejection, strained sexual relations, reduced socializing, shame, economic dependence</p>		
Farid et al. 2013	To investigate the psychosocial experiences of women after fistula development	Qualitative study; eight women on admission for fistula repair	Semi-structure interview using interview guide used. duration 30-90 minutes	Details not provided; article published as "short communication"	<p>Five major themes identified:</p> <p>Physical challenges, psychological challenges, social and interpersonal challenges, religious constraint challenges and financial challenges</p>	<p>-Small sample size</p> <p>-Details of research methodology not provided</p> <p>-Translation bias</p>	-Challenges of living with fistula

Gebresilase. 2014	Investigate the development of survivor's views of their health and social relationship with fistula	Qualitative; using ecological and transactional model of stress and coping framework Purposive sampling and snowballing. Eight women	In-depth interviews using open ended questions. First interview lasted 30-45 minutes, second lasted 40-80 minutes 4-6 days after first. Interviews were audio taped	Audio tapes transcribed, coded, categorized and arranged thematically	Women's gradual change in understanding of causes of fistula. Challenges faced lack of autonomy in life, delay in seeking care during labour. Health and psychosocial issues. Women coped by issue and emotion focused approach. Women develop resilience in	-Ethical consideration with participants identity and confidentiality not detailed - Credibility of findings not discussed; triangulation or participants validation or confirmations by more than one analyst not stated -Subjective nature of qualitative study -Small sample size	- Reintegration experiences of women after fistula repair - Challenges of living with fistula
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<p>Gharoro. E.P & Agholor. K.N. 2009</p>	<p>To assess the psychosocial issues women with fistula and their families experience</p>	<p>Quantitative and qualitative study</p>	<p>Quantitative-structured questionnaire</p> <p>Qualitative : in-depth Interviews</p> <p>30 women and ten members of their families</p>	<p>Coding using SPSS 15</p>	<p>ANC attendance; 5%</p> <p>Knowledge Perceived causes of fistula- obstructed labour 36.67%, prolonged labour 26.66%</p> <p>Psychosocial consequences- loss of job 33.33%, isolation 30%, divorce 16.67%</p> <p>Patient's attitude- bitter & depressed 60%, sad & dejected 20%</p> <p>Relatives attitudes to women- rejection 53.33%, supportive 40%</p>	<p>-Small sample size</p> <p>-Research design detail not provided</p> <p>-Figures presented in the table for psychosocial effects do not correspond with figures quoted in the findings and discussion</p> <p>-Questionnaire not - validated</p> <p>-Triangulation not discussed</p>	<p>-Challenges of living with fistula</p>
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<p>Khisa et al. 2012</p>	<p>-Provide information on challenges women with fistula face after repair</p> <p>-Describe within a larger women's health context the needs of the women</p>	<p>Qualitative; exploratory study</p> <p>Sampling type not stated; 8 women interviewed</p>	<p>Four women interviewed at home, three during visit to rehabilitation centre, one while at centre. Observation of women during home visit. Interviews occurred 1-4years after fistula developed and 3-36 months after most recent repair</p> <p>Two FGDs held; first group, 7 survivors of fistula; second group, 12 men & women participants of a FGM community awareness workshop</p> <p>Audio taping and notes taken</p>	<p>Notes transcribed and translated into English. Using grounded theory data was analysed thematically</p>	<p>Women had varying marital experiences; all the married had period of separation from spouses. All women had low level of education. All women had delivery assisted by unskilled birth attendants.</p> <p>Women all faced stigma leading to psychological trauma. Marital disruption resulted and societal women's worth as mothers diminished.</p> <p>Faced financial difficulties. Women with repair failures felt worse off</p>	<p>-Choice of research design not justified</p> <p>- Data collection methods not justified</p> <p>- Credibility of findings not discussed; triangulation or participants validation or confirmations by more than one analyst not stated</p> <p>- Small sample size</p>	<p>- Challenges of living with fistula</p> <p>-Reintegration experiences of women after fistula repair</p>
<p>Landry et al; 2013</p>	<p>Study lives of women before fistula development and quality of life with and after fistula</p>	<p>Quantitative: Participant selected on consent: 1354 women before surgery 140 – Bangladesh, 251- Guinea, 171- Niger,</p>	<p>Interviews in local language using standardised questionnaire before and three months after fistula repair,</p>	<p>In each country analysis of patients' characteristics and experiences- calculation of frequencies for categorical variables</p>	<p>Some variations across countries in --women's characteristics; majority rural dwellers</p> <p>-At least one ANC between 10.9-90.7%, all countries greater than</p>	<p>-Quantitative study, qualitative would have benefited aim of study</p>	<p>-Challenges of living with fistula</p>

		<p>422- Nigeria, 370- Uganda</p> <p>After repair, 1278 women</p>		<p>and medians and interquartile ranges for continuous variables;</p> <p>Follow up analysis; McNemar paired analysis using STATA 10 by countries</p>	<p>12 hours labour at home, varying structural and sociocultural delays</p> <p>Varying post repair counselling and support services</p> <p>Significant change in living arrangement after surgery less living with husband</p> <p>Drop in ability to support self with fistula, rise after repair</p> <p>At follow up majority improved in most of experiences; changes based on fistula repair outcome</p>	<p>-Choice of research design not justified</p> <p>-Women who receive care may not be representative sample</p> <p>-Self-administered; reporting biases and courtesy bias</p> <p>-Recall biases; missing data as a result of recall issue</p> <p>Short follow –up time; better impact assessment not feasible</p> <p>- Structured questions not allow in-depth</p>	<p>-Reintegration experiences of women after fistula repair</p>
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						understanding of experiences	
Mohammed. 2007	Evaluation of impact of rehabilitation program on women after fistula repair	Quantitative; Program evaluation. Evaluation of records from 1999-2002	First group - 1999/2000: 28 women Second group- 2000/2001: 22 women Third group- 2001/2002: 26 women fourth group- 2002-2003; 11 women fifth group- 2003-2004; 17 women sixth group-2004-2005; 20 women seventh group-2005-2006; 21 women	Evaluation of medical records and report of activities	Treatment; majority of women had successful repair, some needed more than one repair Reintegration and rehabilitation; all the women were involved in literacy classes, gardening and went through vocational classes to learn income generating skills. All the women were reintegrated successfully into their communities after graduation. Follow up of women after reintegration; visits to centre encouraged, also outreach to women takes place 2-3 months after returning home. Out of the 145 women, 25 has had successful	-Study would have benefited from qualitative component -Ethical issues not provided - Methodological details not provided	- Treatment and care experiences -Reintegration experiences of women after fistula repair

					vagina deliveries, with fistula not recurring		
Mselle et al. 2012	To understand women's expectations and reintegration experiences after repair	<p>Mixed methods of quantitative and qualitative</p> <p>Qualitative: convenience strategy, all women admitted in ward during study period asked, eight willing and met inclusion criteria</p> <p>Quantitative: all women admitted in ward asked, none refused, and all met</p>	<p>Qualitative: one time semi structured interviews in Kiswahili for each participant, using interview guide, in private room. Audio taping and notes were taken. Recruitment was until saturation point of data. One participant followed up for 6mths</p> <p>Quantitative: validated questionnaire, pilot</p>	<p>Qualitative: All interviews transcribed verbatim in Kiswahili, translated into English, back translated</p> <p>Thematic analysis of identified codes</p> <p>Quantitative: SPSS (version 15) descriptive analysis, frequencies, cross tabs and chi-square statistics employed</p>	<p>Quantitative: 39% aged 21-30 years, 97% illiterates/ only primary education, 18% divorced, 57% lived with fistula less than 1 year; after surgery, 49.7% planned to return to spouse, 55.0% had hope to have children, future marriage 37.7%, owning a business was 79.5%</p> <p>Low parity, young age, and shorter period of living with fistula</p>	-Triangulation of findings from qualitative and quantitative not discussed	<p>-Reintegration experiences of women after fistula repair</p> <p>- Treatment and care experiences</p>

		the inclusion criteria. 151 women	tested translated into Kiswahili with close ended questions,		positive association with desiring a child Qualitative: lived longer with fistula, many not willing to return to husbands; hopes for children in future; some do not desire renewal of friendship, others hopeful to restore to normal life. One participant followed for 6mths; happy with surgical outcome, restored to normal life but unable to survive economically without assistance		
Muleta et al. 2008	To assess health, social and psychological challenges faced by women treated and with obstetric fistula in rural Ethiopia	Cross sectional survey; quantitative and qualitative Quantitative: Five stage sampling technique, random sampling, and estimated sample size of 18,000.	Quantitative: fistula presence verified at health House to house surveys; using two different questionnaires Qualitative: in-depth interviews in native language using question guides, audio recorded,	Quantitative: not stated- demographic data presented as frequencies Qualitative: coded and analysed by themes	Quantitative: sociodemographic data tables Qualitative: for all; first sexual encounter unpleasant experience, delayed long labour Untreated: had incontinence urine and faeces; 11 had heard	-Data analysis process not discussed -Triangulation of findings from qualitative and	- Challenges of living with fistula

		Qualitative: 39 women with fistula and 13 women that had repaired fistula. Interviews	transcribed verbatim, and translated.		about repair services; 21 divorced, 2 no longer live in same house & 16 do not attend community meetings; differing experiences (positive & negative) with spouse & family support. Treated: positive family experience. Both group limited knowledge on cause of fistula; all were psychological impact of news of fistula	quantitative not discussed	
Mwini-Nyaledzigbor et al. 2013	To explore and describe experience of living with fistula from perspective of the women	Qualitative study using purposive sampling of ten women with fistula	Unstructured interview; open ended questions using an interview guide	Content analysis; to identify themes and categories	Description of women Cultural beliefs /practices predisposing to prolonged labour Challenges of living with fistula; psychosocial, economic, physical Access to health care issues	-Small sample size -Translation bias	-Challenges of living with fistula -Treatment and care experiences

Nathan et al; 2009	-Understand obstetric fistula through views of patients	Quantitative: Sampling type not mentioned. 37 women agreed to participate	Open-ended questionnaire; structured interviews conducted using questionnaire with the help of interpreter	Not stated	Demographic characteristics; Poor prenatal care during pregnancy; long labour and delayed getting to health facility Causes of delivery trauma; financial constraints hindrance to care. Financial assistance not sought for reintegration, but economic assistance	-Language barriers and small sample size -Could have included qualitative -Ethical considerations for women not rigorous -Research design choice not justified -Recruitment process not described -Data analysis not described -Findings not discussed critically	- Treatment and care experiences - Reintegration experiences of women after fistula repair
Nielsen et al. 2009	-Assess reproductive and urinary health	Quantitative; community-based structured interviews;	Interviewer filled questionnaire 14-28 months after surgery; pilot tested	Not described, but Wilcoxon signed rank test for paired data used in comparing QOL	Urinary; 57% totally dry, 35% varying degree of	-Low sample size	-Reintegration experiences of

	-Assess quality of life of women after fistula repair	List of names given to identify women with fistula; 38 women identified for follow-up	questionnaire for urinary and reproductive health, and validated assessment tool; Kings health questionnaire for QOL, women with urinary incontinence	data before repair with data while with fistula, and data at follow up with data living with fistula	incontinence,3% had fistula Quality of life: significant improvement for those dry and incontinent, while no improvement for those with fistula Reproductive health; 71% remained married & sexually active, 26% amenorrhoeic, 11% used family planning ,33% became pregnant	-Recall bias -Courtesy bias -Choice of research design not justified - Non- validated tools for data collection -Details on data management and analysis not provided -Ethical considerations not rigorous.	women after fistula repair
Pope et al. 2011	-Explore meaning of successful repair to women with obstetric fistula and factors related to capacity to return to normal life	Mixed method of quantitative and qualitative Purposive and snowballing of three groups	Qualitative: semi structured interviews and social map, at location of participant choice for two about hours. Interview was in Swahili. Audio taping for all except one participant	Quantitative: data was captured in excel sheets, analysis was by SPSS Qualitative: interview notes compared by two researchers, translated into English, reviewed against the	Both results presented thematically -Returning to roles and responsibilities; majority had recovered to normal life -Social roles after repair: majority of women no longer interested in	-Choice of research design not justified -Language and interpretations introduce inaccuracies	- Challenges of living with fistula -Reintegration experiences of women after fistula repair

		<p>Group 1; 25 women treated but back to community</p> <p>Group 2; 25 women, control group</p> <p>Group 3; 21 women waiting for repair</p>	<p>Quantitative: validated and modified questionnaires, PQoL (Patrick, 2000) and RNLI (Daneski et al, 2003); converted into pictorial form for non-literate women</p>	<p>audio recordings. Analysed thematically</p>	<p>marriage or men, some still desire children but fear fistula recurring</p> <p>-Long term effects of fistula; bodies not the same</p> <p>Access to follow up services; not available after discharge</p> <p>Family support: successful repair linked to support from family</p> <p>-Time factor in healing process; statistically significant correlation for increased PQoL & RNLI with period of time post repair</p> <p>-Incontinence after repair; incontinent had lowers scores</p> <p>-Social stigma and community involvement; some stayed away from people, but low levels of rejection by community,</p>	<p>- Although tools validated, it has not been validated in use for women with fistula, or in Tanzania</p> <p>-Small sample size</p> <p>- Control group might be non-representative sample</p>	
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Siddle et al. 2012	Assess psychosocial impact of fistula	Quantitative study; retrospective study	Questionnaire administered on admission in Kiswahili Data entered in English in excel sheet	Descriptive statistics	Loss of child 92% Trauma over child loss 56% Feeling wet 91% Loss of self-confidence 56% Loss of self-worth 68%	-Small sample size -Data collection tool not validated -Translation bias -Comprehensive statistical analysis of results not done	-Challenges of living with fistula
Turan et.al. 2007	Present experiences of women to - provide direction on community mobilization and safe motherhood education strategies; improve services provided for women with OF	Qualitative and quantitative Purposive sampling; 11 women and 5 family members waiting for repairs 15 women for follow-up	Open ended interviews using interview guides for women and the family members waiting for repairs in private rooms; discussions audio taped, transcribed by native language speakers to English. Semi structured interviews 6-10 months post repairs using a questionnaire with	Open ended interviews coded & analysed with Ethnographic qualitative analysis software program (5.07) Semi-structured interviews, data entered in Excel worksheet, analysis by SPSS (12.0)	Characteristics of women; for repair group- majority 20 years or less and primigravidas at OF occurrence, still married, no formal education lived with fistula 1-30years. Follow up group; mean age 27, 53% divorced, married 33% Long and complicated delivery at home, delays to seek care in hospital Not knowledgeable about cause of fistula	-Interviews translator facilitated -Likelihood of bias introduced by being polite in not expressing dissatisfaction, -Recall bias possible -Only 23.4% followed up cases studied;	-Treatment and care experiences of women -Reintegration experiences of women after fistula repair

			closed and open-ended questions		<p>Negative experience after fistula development</p> <p>Limited information at treatment</p> <p>Majority satisfied with repair, but experiences vary</p> <p>Eritrea situation affects women</p>	<p>complicated cases interviewed</p> <p>-Methods used not justified.</p> <p>-Methodological orientation not stated</p> <p>-Triangulation of qualitative and quantitative not stated</p> <p>- No mention of ethics committee approval</p>	
Umioyoho et al, 2011	-Assess and compare the quality of life of women after successful repair of fistula	Quantitative All women obtaining care during study period; 265 were willing, only 150 women returned for follow up	Questionnaire that was pre-coded and pre-tested was used for demographic data and WHO QOL –BREF questionnaire, this was repeated at 6-month follow-up	Data was analysed using inferential and descriptive statistics	<p>Women were older, multiparous and majority still married and had secondary education</p> <p>Improvement in the physical area, mental health but not significant</p>	-Successful repair not defined in context of the study	- Reintegration experiences of women after fistula repair

					improvement statistically in environmental area	<ul style="list-style-type: none"> -56.6% of initial study group returned for follow up -Returning women might have issues needing further attention -Recall bias -Short follow-up period of 6 months -Courtesy bias; providing answers to please health providers 	
Velez et.al. 2007	<ul style="list-style-type: none"> -Summary of needs assessment by UNFPA -Raise awareness and obtain programming information and 	Qualitative and quantitative;	Survey questionnaire, country Policy documents (MIC, UNICEF Surveys, 2001,2000, 1999, DHS), records, site visits, FGDs,	Not described	<ul style="list-style-type: none"> Identified causes; limited access to care, underlying cause poverty; sociocultural & geographical factors Inadequate treatment for fistula 	<ul style="list-style-type: none"> -Summary findings presented hence, distinct differences between countries veiled 	-Treatment and care experiences

	advocacy for obstetric fistula		IDIs/narratives, key informant interviews		Community not knowledge about fistula Socioeconomic consequences-Women stigmatized & rejected Inadequate reintegration and rehabilitation services	-Details on research design sketchy	-Challenges of living with fistula -Reintegration experience of women after fistula repair
Women's Dignity project and EngenderHealth. 2006	-Understand the complexity surrounding fistula and its social consequences through the lives of the girls & women affected, their family, community and care givers in health facilities	Qualitative Identified and contacted 61 Women and girls, 42 family members of the women and girls, 68 community members living close to women and girls, and 23 service providers in facilities close to women and girls	In-depth interviews, group discussions, free listing, and problem trees Interviews were in Swahili using pretested tools, meetings took place in homes and hospitals; lasting 2 hours. Note were taken by note taker	Notes were reviewed and transcribed after interviews. Codes book was developed and used. Atlas-ti was used for producing the final text. Feedback meeting were held with all participants.	Majority of women attended ANC at least twice and planned to deliver in facility. But few made exigency plans for delivery. Majority laboured at home with delays to get care. All the groups had differing views on causes of fistula. Effect of fistula; Marital status remained basically same, stigma and isolation resulted. Economically fistula had	-Recall bias; Some women lived with fistula for long, might not remember detail about labour -Hospital based entry, might not be representative sample; experiences of those isolated might not have been captured	-Challenges of living with fistula -Reintegration experiences of women after fistula repair

					<p>effect on women and their families. Care was sought by women from traditional healers; some had repairs that were not successful. But for majority successful repair had dramatic effect on women and family, not same for unsuccessful repair</p> <p>Recommendations were provided for prevention and treatment.</p>	<p>-Researchers had limited research experience</p> <p>-Audio taping not done</p> <p>-Detailed questions on labour experience not asked</p>	
Yeakey et al. 2011	Provide understanding of perspectives and experiences of women, spouses, female relatives with and after fistula repair	<p>Qualitative</p> <p>Through hospital record, use of key informants in communities and snowballing</p> <p>First round 47 women with fistula, 5 women post repair, & 30 family members; 4 records lost to technical problem, number reduced. On follow up interview, 18 women post repair</p>	In depth interviews in Chiyao by trained interviewers for 30-90 minutes with audio taping	Interviews transcribed and translated manually from recordings from Chiyao to English. Typed into word document, coded themes, and subthemes manually. Analysis by open coding using emerging domains	<p>Demographic characteristics; before surgery- mean age 37years, 60% married, 35% had no living children</p> <p>After surgery- mean age 30 years, 65% married, 475 same husbands, 1.3 average of living children</p> <p>Women perspective:</p> <p>Before surgery- descriptions of physical conditions and</p>	<p>-Short follow up time 4 months post-surgery.</p> <p>-Studied only those supported, did not include those abandoned</p> <p>-Translation bias</p>	<p>-Challenges of living with fistula</p> <p>- Treatment and care experiences</p>

		and 11 family members			<p>consequences. After surgery- improvement in conditions even for those partially cured</p> <p>Difficulty in getting repairs services; long waits and repeated efforts</p> <p>Family perspective; before surgery-grief and helplessness. After surgery-positive impact on women and happiness</p> <p>Husbands- before surgery- grave concern and hope in recovery</p> <p>After- relief and joy</p>	- Details of women's ethical considerations not stated	
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2.2.1 Part One: Methodological Quality

A total of 25 articles were reviewed; out of these, nine were quantitative studies, nine qualitative, and seven used mixed methods. The assessment of the methodological quality of the studies was guided by the use of the Critical Appraisal Skills check list programme (CASP) for qualitative studies, quality in qualitative health research (Pope and Mays, 1999) and Evaluation tools for quantitative research and mixed method studies (Long, 2005). Even though the word count limitation by journals might make detailed presentation difficult, some studies were able to provide clearly written reports of significant methodological quality. Some others however, demonstrated a limited ability to achieve this.

Generally, the following observations were made about the studies that were reviewed; the settings for the studies were described; participants were identified mostly at the facility and some few others through key informant in the community. This provided the required contextual basis for the findings. However generally, there was limited application of reflexivity on the part of majority of the authors that carried out the qualitative research; attention was not paid to the subjective role of the researcher in the research process (Nettleton, 1995). Apart from the studies in the UK and US, all the data collection tools were administered using the native languages and translated into English for analysis. However, not all the authors discussed this as a limitation. Based on the evaluation tools assessment criteria (listed above), the methodological quality of the studies is grouped into three categories; high, medium and unascertainable quality:

High quality:

Overall, the Women's Dignity Project and EngenderHealth (2006) achieved appreciable trustworthiness in their paper. This study had the highest credibility in this review. It was a qualitative study with a robust research design that used four methods and interviewed four different groups of participants. Data analysis was rigorous and participant feedback was utilized. The qualitative study by Muleta et al (2007) had the most rigorous sampling method among all the studies. To identify women with treated

and untreated obstetric fistula, a house to house survey was carried out. This involved using a five-stage sampling method. In all, over 19,000 houses with a population of over 97,000 persons were visited. Data was collected using in-depth interviews of two different sample groups. Additionally, they assisted women with untreated fistula or treated with health challenges by providing transport money to access treatment at the hospital.

Equally in this group of studies with high trustworthiness, was the study by Alio et al (2011); this was a qualitative study of the lives of 21 women. This study was carried out using an ethnographic approach; details of how it was undertaken in the data collection and analysis was provided; steps were taken to ensure appropriate interview protocols. Details of the ethical approvals from the ethics board and steps taken to uphold ethical standards with participants were provided. Another study that demonstrated high credibility was that by Pope et al (2011), they used mixed methods of study. Three different sample groups that included a control group were used. They were able to triangulate the findings of both methods. One of the qualitative studies in this group with demonstrable trustworthiness was by Yeakey et al (2011). This study used in depth interviews with three different sample groups with two different rounds of interviews. The interviews were conducted in homes (confirmed via email with corresponding author). Furthermore, triangulation of the findings from the different groups was done. Equally, saturation of data was discussed. Noteworthy was the use of feedback at different stages of research (design, data collection and analysis). This was done with community members appointed as investigators.

The study by Mselle et al (2012a) also demonstrated high credibility. They conducted a mixed method study. Two sample groups and two data collection tools were used. In addition to the main interviews conducted in the facility, two participants were followed up for interviews first in the facility and later at their homes. One of these interviews involved a home visits for six months, with a night of observation spent in participant's home. Data analysis was rigorous, and details were provided. Furthermore, triangulation of the various findings and data saturation was discussed.

The study by Mwini-Nyaledzigbor et al (2013) also demonstrated a high degree of trustworthiness. The aim of the study was to explore the perspective of women with fistula on their experiences; hence the choice of a qualitative methodology was appropriate for the study. The research design was clearly justified, and the recruitment strategy was appropriate for the study aim. Furthermore, the settings and methods for data collections were described and justified. Data saturation was discussed, and steps taken for ethical considerations were provided. Details of data analysis were given, and the findings were explicitly discussed in relation to the research question. The study by Gebresilase (2014) was another qualitative study that also demonstrated a high level of trustworthiness. This was a qualitative study that clearly justified its choice of research design. Additionally, the methodological grounding of the study was explained in detail. The interviewing details and approach to data management were provided. Furthermore, ethical consideration was thorough, and the data analysis detail was discussed.

Among the quantitative studies, the study by Landry et al (2013) had the highest trustworthiness. This study was rigorous in methodology and presentation of its findings. The research was a 5-country study that had a large sample size of over 1,300 women. The same data collection tool was used in all the 11 study sites. The data analysis was rigorous, and findings were analysed critically across the different countries. Hence, the generalizability of the findings of this study is possible. But based on the research question, inclusion of qualitative design would have helped in understanding the aspect of the experience of the women thereby making the study more robust. The authors equally noted this as a limitation.

Finally, in this category, were the quantitative studies by Dolan et al (2008) and El-Gazzaz et al (2010). These were the only studies carried out in developed countries in this review. In both, the research designs were rigorous, and the details of data analysis were provided. Based on the setting, a more technological relevant method of data collection of administering questionnaire via post and telephone were employed.

Medium quality:

The next group are those studies that demonstrated some level of credibility but were less rigorous in the research design compared to the first group above. Hence would be suggestive of studies of medium quality. In this category is the study by Turan et al (2007). They used two data collection methods and three sample groups. However, the methodological approach was not justified and how triangulation of the different findings and methods were carried out was not discussed. In the study by Browning and Menber (2008) a structured questionnaire was employed, for the follow-up study. The authors admitted the tools used were not validated (Browning and Menber, 2008). Furthermore, the choice of research design and methodology were not justified.

Another study in this category is the long-term community based follow up by Nielsen et al (2009). For this study however, not all the interviews were conducted in the community. A little over half were done in homes while the rest were in the facility; there was no explanation on why the community based follow up included interviews in the facility. The initial assessment for participants' enrolment was through key community informants, government ministries, hospitals and radio announcements. In the final follow up study, they recorded a high follow up rate of 86% for the initial women enrolled in the cohort. However, data analysis details were not provided, and ethical consideration was not rigorous. This was a quantitative study; inclusion of qualitative study could have provided a more robust research finding on women's 21 months experiences after returning to their communities.

In this category of studies of medium trustworthiness was also the study by Umioyoho et al (2010). They used a validated tool for data collection pre- repair and six months after repair as follow up. However, the choice of research design was not justified. Equally the details of ethical consideration to participants were not stated. Another study in this category was the two countries qualitative study by EngenderHealth (2012). The settings were clearly presented, setting the stage for a clear contextual presentation of their findings. Details for data collection methods and ethical considerations were provided. Except that details for the data analysis was not stated. Equally in the method, it was mentioned that focus group discussions were held for women that escorted the

women with fistula for repair, community members and a men's group. But the findings were centred mainly on the women with fistula; no reference was made to any other group. In the study by Khisa et al (2012), two different sample groups were interviewed, and three data collection methods was used. However, the choice of research design and methodology were not justified. Furthermore, the details of data analysis and triangulation of the findings from the different groups and data sources was not discussed.

Again, in this group was the study by Siddle et al (2013). This was a retrospective study, from routinely collected data. Their data collection and analysis methods were provided. However, details of obtaining informed consent from the women were not given. The data collection tool used was not suitable; this tool was developed to assess the impact of fistula, and not a validated tool to assess psychosocial impact. Again, a multivariate analysis of the variables would have provided a better analysis than the descriptive statistics that was used. Finally, in this group was the study by Donnelly et al (2015), the report mentioned that mixed method of a facility-based survey and community-based interviews were done. But only the community-based interviews method was discussed. Contact via email with the corresponding author revealed the facility-based survey's findings were not included. However, the study was carried out in four different sites and the community-based research methodology was provided. Furthermore, the details of the ethical considerations and data analysis were provided. Validation through feedback with a community team was included as part of the data analysis process.

Low quality:

In the group that demonstrated the least rigor and trustworthiness was the study by Nathan et al (2009). The research objective of this study was to assess patient perspectives on obstetric fistula. A quantitative method of structured interview using open-ended questionnaire administered by physician was used. A qualitative study would have been better in gaining the insight desired. The choice of method of data collection and research design were not justified. Also, details of ethical considerations and data analysis were not provided. Furthermore, sample size was small (37 participants) for a quantitative study, and the sampling method was not discussed. The

study by Gharoro and Agholor (2009) also generally lacked rigor in the research design. The study aim was to evaluate the perspective of the women and their families on psychosocial problems associated with fistula. But from the results presented emphasis was placed on the quantitative results. The qualitative results were in the appendices and there was no triangulation of the findings of both methods. Equally sampling methods, ethical consideration details and data analysis details were not provided. The details of the data collection methods were also not provided. Some of the results provided in the table on psychosocial effects did not tally with the figures quoted in the findings. Therefore, this study fitted in to the category of study with least trustworthiness.

Unascertainable quality:

In the final category were those studies that their methodological quality could not be ascertained. Fitting this category was the study by Mohammed (2007). This study appeared to be a description of a program evaluation; data presented were suggestive of report findings of a rehabilitation program in Nigeria. The information on women's personal experiences were not self-reported. Equally ethical considerations were not stated. Efforts to communicate with the corresponding author proved abortive; the email address and phone numbers provided could not be reached. The studies by Bangser (2007) and Velez et al (2007) however, had findings suggestive of a rigorous research but were presented as a summary of studies. Velez et al (2007) carried out a needs assessment study in 20 countries, while Bangser; summarized findings of four different studies in two different countries. With the details not provided, it was difficult to assess the overall quality of the research methodology. The details lacking included, sampling methods and size, details on data collection methods and analysis, ethical considerations and justification of research design. Finally, in this category was the study by Farid et al (2013); this study was a qualitative explorative study but it was published as a short communication in a journal, hence all the details that was needed to ascertain its methodological rigor was absent. Efforts were made to ascertain this information from all of the authors in this category via email, but there was no response till date. Hence based on lack of these details, methodological quality cannot be confirmed.

2.2.2 Part Two: Themes in the Research

1. Challenges of Living with Fistula

In all the studies, the experience of living with fistula was presented often as multi-dimensional negative experiences that affected not only the woman but also her family and community. However, cases vary, with some few exceptions of women not being subjected to negative treatment (Women's Dignity Project and EngenderHealth, 2006, Bangser, 2007). The period of living with fistula ranged from one month to greater than ten years (Women's Dignity Project and EngenderHealth, 2006). These experiences were as follows:

Psychosocial Experiences

The most widely reported challenges were the psychosocial consequences of fistula. These were the stigma, physical isolation and loss of status as a result of the associated physical changes of fistula (Women's Dignity Project and EngenderHealth, 2006, Turan et al., 2007, Muleta et al., 2008, Alio et al., 2011, Khisa and Nyamongo, 2012, Gebresilase, 2014). The incontinence of urine or faeces meant constant wetness, with the smell of urine and faeces being repulsive both to the husbands, family members and people in the community (Women's Dignity Project and EngenderHealth, 2006; Muleta et al, 2008; Alio et al, 2011; Mwini-Nyaledzigbor et al, 2013). The wetness and offensive smell, according to Siddle et al (2013) had the most distressing effect on the women. The women were shunned, insulted and even excluded from activities, which had a profound psychological effect on them (Mwini-Nyaledzigbor et al, 2013). Khisa et al (2012:61) argued that the women were labelled as "damaged" or "spoilt"; being considered valueless as women hence losing their social status. Feelings of depression, worthlessness and sometimes suicidal ideation were reported (Alio et al., 2011, Siddle et al., 2013). The inability to engage in religious activities like prayer worsened the feelings of distress among the women (Farid et al, 2013; Siddle et al, 2013); this was particularly worse for the Muslims, because of the incontinence the women are considered unclean and are hindered in performing religious rites (EngenderHealth,

2012, Farid et al., 2013, Siddle et al., 2013). According to Gebresilase (2014) in this psychological challenge experience; the body becomes a barrier leading to the loss of independence. Consequently, the inability to carry on normal daily activities and fulfilling their role as a wife as expected in the society, had a profound effect on their relationships (Gebresilase, 2014). These experiences contributed to family members experiencing psychological stress. Family members were concerned and anxious for the plight of their wives or daughters as might be the case (Women's Dignity Project and EngenderHealth, 2006, Turan et al., 2007, Yeakey, 2011).

The experience of loss of social support as a result of isolation and expulsion from community and homes was also highlighted (Turan et al., 2007, Alio et al., 2011). Nonetheless in few of these cases, a female family member and sometimes children provided some form of support (Alio et al., 2011). However, four of the studies reported total alienation of the women was not in all cases (Women's Dignity Project and EngenderHealth, 2006, Bangser, 2007, Muleta et al., 2008, Pope et al., 2011). For instance, Pope et al (2011) alleged that majority (95%) in the group of women recently undergoing repair had reported that they were not subjected to mistreatment in their communities. Some women remained with their families but isolated themselves from some communities' members and activities (Women's Dignity Project and EngenderHealth, 2006). In a study in Ethiopia, some women could still eat and interact with family members (Muleta et al., 2008). Bangser (2007: S17) asserted that majority of the affected girls and women still had "financial and emotional" family support.

Marital; reproductive and Sexual Life

Three of the studies argued that in most of the cases, fistula development led to marital disruptions, rejections and total isolation from families (Alio et al., 2011, Khisa and Nyamongo, 2012, Mwini-Nyaledzigbor et al., 2013). Fistula interferes with sexual relations and could have contributed to marital disruption (Landry et al., 2013). In polygamous circumstances as reported by Mwini-Nyaledzigbor et al (2013) even though the women were still living with their husbands, sexual relationships ceased after the development of a fistula. The Women's Dignity Project and Engenderhealth (2006) study reported sexual difficulties were because of the smell and soiling from incontinence.

Some women who continued with sexual relationship highlighted issues of embarrassment from leakages whilst others viewed it as torturous to please their partners (EngenderHealth, 2012). However, Turan et al (2007) and Mwini-Nyaledzigbor et al (2013) in their studies reported that women complained of physical symptoms like genital itch, soreness, dyspareunia, burning sensation and other symptoms like pus and blood in the urine. The most frequently reported sexual dysfunction symptom among those still sexually active was dyspareunia (Browning and Menber, 2008).

Studies by Women's Dignity Project and Engenderhealth (2006), Muleta et al (2007), Yeakey et al (2011), Landry et al (2013), and Donnelly et al (2015) reported some husbands remained supportive, living with their wives despite the fistula. But women who suffered rejection usually returned to their birth homes (EngenderHealth, 2012, Landry et al., 2013). In the study in South Nigeria all the women (120) remained married while living with a fistula (Umioyoho et al., 2011b). Similarly, in the study by Women's Dignity Project and EngenderHealth (2006) in Tanzania, the majority remained married except for those that sustained fistula as a single woman – these women never married. Landry et al (2013) feel that the earlier assumption on high marital disruption was disputable. However, Turan (2007) and Pope et al (2011) believed presence of children contributed to some women not losing their homes. Hence suggesting this might be the case with the study by Umioyoho et al (2011); majority of the women (66.7%) in this study had more than five children. However, data on number of living children in the Tanzania study by Women's Dignity Project and EngenderHealth (2006) was incomplete to allow for further assumptions. Therefore, it is still doubtful to conclude that there is total marital disruption and isolation for all women with fistula. Some girls and women still enjoy support from husbands, family members and friends (Women's Dignity Project and EngenderHealth, 2006).

Quality of Life

In the review, different tools were used by the studies to investigate the quality of life. But generally, the quality of life was lower for women living with a fistula. In the study by Nielsen et al (2009: 1260) a validated tool known as "King's Health Questionnaire" that measures the quality of life in women with urinary incontinence was used. The tool

was translated into the local language. The quality of life was statistically significantly lower while living with fistula ($p=0.001$); the lowest scores were for areas that measured the level of social interactions. On the other hand, Umioyoho et al (2011) used the World Health Organization Quality of Life (WHOQOL BREF) questionnaire that measured the quality of life in the areas of physical, mental, social and environmental health. The lowest score in this study was also in the social health domain followed by the mental health (Umioyoho et al, 2011). In the study by Pope et al (2011), quality of life was measured using the Perceived Quality of Life tool (Patrick, 2000). The calculation of quality of life was based on a 10-point scale ranging from “completely unhappy to completely happy” (Pope et al, 2011: 862). The tool was modified to suit the rural Tanzanian context and a pictorial version was used for non-literate women (Pope et al, 2011). The tool investigated the physical, mental, level of social support and financial wellbeing of the women. Furthermore, a comparison of the perceived quality of life (PQoL) was investigated among three groups, women with repaired fistula, women without fistula (control group) and women in hospital for repair. Women in hospital for fistula repairs had the lowest score. These women had a decrease in scores from the period before fistula to the period after fistula development. The psychosocial challenges led to “loss of control” over normal daily activities (Gebresilase, 2014:1037)

Socio-Economic Experiences

The experience of living with fistula was linked with the inability to work as a result of stigma or ill health (Mwini-Nyaledzigbor et al., 2013). This led to economic hardship for the majority of the women and their families (Women's Dignity Project and EngenderHealth, 2006, Turan et al., 2007, Landry et al., 2013). It equally contributed to their dependence on others for survival (Women's Dignity Project and EngenderHealth, 2006, Khisa and Nyamongo, 2012). Furthermore, their condition meant utilizing more resources to cater for the need to maintain cleanliness (Women's Dignity Project & EngenderHealth, 2006; Yeakey et al, 2011; Mwini-Nyaledzigbor et al, 2013). Consequently, all of these contributed to financial drain on the family's meagre resources and some incurring debts (Women's Dignity Project and EngenderHealth, 2006, Mwini-Nyaledzigbor et al., 2013). However, at the same time, Nielsen et al (2009) reported some women; mainly farmers (92%) could continue their income generating

activities while living with fistula, with only 22% not working. Pope et al (2011) opined that financial hardship was more pronounced for those that lacked financial independence before developing fistula and those that lost their homes. Interestingly in comparing the socioeconomic differences between women in Bangladesh and Democratic Republic of Congo (DRC) in the study by Engenderhealth (2012); they observed that DRC women had more financial freedom and autonomy, despite the fistula, and could still engage in financial activities.

Coping with Fistula

In living with a fistula, women developed various coping mechanisms for the hardship of daily existence (Women's Dignity Project and EngenderHealth, 2006, Mwini-Nyaledzigbor et al., 2013, Gebresilase, 2014). Four studies looked specifically at this issue - Women's Dignity Project & EngenderHealth (2006), EngenderHealth (2012), Mwini-Nyaledzigbor et al (2013) and Gebresilase (2014). Some of the mechanisms were described as learning to deal with the physical difficulties of wetness and smell, by washing and changing clothes, use of perfumes, lotions, 'padding' and bathing (Women's Dignity Project and EngenderHealth, 2006, EngenderHealth, 2012, Mwini-Nyaledzigbor et al., 2013). As a result, sourcing for water in areas with scarcity became an issue to both the women and their families (Women's Dignity Project and EngenderHealth, 2006). Other coping strategies include restricting the intake of fluid and food, the use of plastic bags to cover the protective cloth used for padding, and sometimes putting sawdust in the plastic bag to absorb the flow (EngenderHealth, 2012). Others were avoiding people and considering how well protected from leakage they were before sitting in public (EngenderHealth, 2012). These strategies were noted to be ineffective in managing the wetness and smell (EngenderHealth, 2012).

From a different perspective, Gebresilase (2014) described the "problem focused" and "emotion focused" coping mechanisms theoretical concept by Folkman and Lazarus (1980). The "problem focused" involved productive techniques such as family support, disposing of possessions and "orientating to reality" (Gebresilase, 2014: 1038). On the other hand, "emotion focused" approach involved isolations, suicidal ideations or

attempts and adopting a positive attitude. These mechanisms, Gebresilase (2014) alleged helped the women to deal with the fistula before and post repair.

2. Treatment and Care Experiences of Women

Care Seeking Experiences.

Fistula treatment experiences were highlighted in two of the studies as a long and frightening journey (Women's Dignity Project and EngenderHealth, 2006, Yeakey, 2011). It involved several failed attempts to get the right care (Women's Dignity Project and EngenderHealth, 2006, Alio et al., 2011). Such attempts might have included patronizing traditional healers and several visits to the same or different facilities (Women's Dignity Project and EngenderHealth, 2006, Yeakey, 2011). Mwini-Nyaledzigbor et al (2013) however asserted that in addition to financial constraints and lack of professional care at hospitals within their reach, access to care was limited by lack of knowledge on the availability of repair services. These contributed to the women resorting to traditional remedies (Mwini-Nyaledzigbor et al., 2013). Care was also sought by purchasing medicines across the counter (EngenderHealth, 2012).

In the 20 countries study, Velez (2007) observed that both human resources and infrastructural services were lacking at the hospitals. Consequently, Velez et al (2007) claimed that this limits the number of women that can be treated. Furthermore, physical access in terms of transporting from remote villages was considered a huge hindrance to obtaining care (Bangser, 2007, Velez et al., 2007). According to Siddle et al (2013) provision of transport fee contributed to a 65% increase in the number of repairs in the study site a year after the introduction of the transport scheme. There is huge backlog of women seeking repair across the countries (Velez et al., 2007). Even though cost is usually subsidised or free, Yeakey et al (2011) opines that the bureaucratic hurdles women and their families had to scale limited access to treatment (Yeakey, 2011). EngenderHealth (2012) observed that all the four women in the Bangladesh study refused the offered free repair services; these women were older and had had several failed repair attempts. On the other hand, in the same study, all the women in DRC study who were younger accepted the offer of free repair (EngenderHealth, 2012).

The attempts to seek a cure were not done in isolation, for women most often must be accompanied by a family member (Women's Dignity Project and EngenderHealth, 2006, Yeakey, 2011). The family and community support provided ranged from assisting during treatment, providing money, helping with chores and giving emotional support (Women's Dignity Project and EngenderHealth, 2006, Bangser, 2007, Pope et al., 2011). Therefore, challenges in seeking cure might be hindrances to care for those women without family support (Women's Dignity Project and EngenderHealth, 2006, Yeakey, 2011).

Treatment Management Experience.

On arrival at the facility, treatment is usually by surgical repair (Alio et al., 2011, Yeakey, 2011). The outcome of the surgical repair led to varying degrees of continence for the women (Women's Dignity Project and EngenderHealth, 2006, Turan et al., 2007, Donnelly et al., 2015). The findings in three of the studies revealed that successful closure with no leak varied, ranged from 13% to 82% (Women's Dignity Project and EngenderHealth, 2006, Turan et al., 2007, Donnelly et al., 2015). Four of the studies reported that women had one to three repairs before becoming continent, while some remained incontinent after the attempts (Alio et al., 2011, Yeakey, 2011, Khisa and Nyamongo, 2012, Donnelly et al., 2015). The several failed repair attempts contributed to some of the women getting discouraged and losing hope (EngenderHealth, 2012). However, some women had continence restored over time after discharge (Browning and Menber, 2008, Muleta et al., 2008, Yeakey, 2011). Surgical repair contributes to improved psychological well-being of the women; expressed as joy, deep sense of relief and gratitude (Donnelly et al, 2015). Yeakey et al (2011) argued that the surgical repair experience was defined more by the social change in status than by the physical change in status.

The social status change was described as the ability to interact with family and friends, and restored value as a woman; in this society, this meant the hope for future deliveries (Alio et al, 2011, Yeakey et al, 2011). Two of the studies reported that women were generally satisfied with the fistula repair despite the level of continence (Turan et al.,

2007, Yeakey, 2011). On the contrary, in the study in Kenya, it was alleged that women felt worse off after unsuccessful repairs (Khisa and Nyamongo, 2012).

The treatment experiences also involved various forms of psychosocial support. A psychosocial support most commonly described is the interaction with their peers on arrival at the facility for treatment. Meeting other women in their condition had the most profound healing effect on the women (Alio et al., 2011, Gebresilase, 2014); this usually was the first sign of hope for a cure on arrival. This was a psychological healing process that continued throughout the period of treatment and after (Alio et al., 2011, Gebresilase, 2014). Gebresilase (2014) describes this experience as an additional “coping strategy for subjective positive interpretation”; wherein by observing the changes in the lives of their peers, helps them adapt to changes associated with fistula experience (Gebresilase, 2014: 1039). Hence, women who were successfully repaired became advocates for facility repair, not only in the treatment centres but also in the community (Alio et al., 2011, Yeakey, 2011, Donnelly et al., 2015).

Another psychosocial support discussed in the articles reviewed, was that provided by the family during treatment. As discussed earlier, this was provided by those that assisted while the women were living with fistula (Women's Dignity Project and EngenderHealth, 2006, Yeakey, 2011, Gebresilase, 2014). Yeakey (2011) alleged that the few women without this support faced emotional and financial difficulties. Another form of psychosocial support provided during treatment is post repair rehabilitative counselling. But it was observed that this was not the practice in all fistula repair facilities (Yeakey, 2011). From the studies, advocates believe post repair rehabilitative counselling is most critical for effective reintegration (Mohammad, 2007, Muleta et al., 2008, Alio et al., 2011, Yeakey, 2011). Donnelly et al (2015) described post repair rehabilitative counselling as an essential part of the holistic management care approach for fistula treatment.

3. Reintegration Experiences of Women after Fistula Repair

Post Repair Support Services (Reintegration Services)

Post repair psychosocial support services that include rehabilitation program are believed to be beneficial for reintegration (Mohammad, 2007, Alio et al., 2011, Mselle et al., 2012, Landry et al., 2013, Donnelly et al., 2015). These services are targeted towards ensuring successful reintegration (Pope et al., 2011). Authors suggested that treatment for obstetric fistula should include reintegration support and organized follow up (Muleta et al., 2008, Alio et al., 2011, Pope et al., 2011, Khisa and Nyamongo, 2012). On the other hand, Nathan et al (2009) alleged women had no need for reintegration assistance, emphasizing that successful surgical intervention was sufficient for reintegration. Similarly, in the Malawi study, even though women did not undergo a post repair rehabilitation counselling, the women experienced limited hindrances in reintegration (Yeakey et al, 2012). In the review, a facility-based approach appears to be in use in providing this support. It is uncertain whether there exists a standardised structure for post repair support services for fistula care (Donnelly et al., 2015). Velez (2007) asserted that reintegration and rehabilitation service provision, across the 20 countries studied, was grossly inadequate.

Table 2.3: Reintegration services in fistula treatment

Author	Follow up period post repair	Reintegration efforts/services	Observations
Nielsen et al, 2009	21 months	-Post repair counselling on sexual and reproductive health -Contraception provided; vouchers provided for delivery	-Reintegration experience based on data from structured questionnaire - Women's perspective not captured
Gebresilase, 2014	Not stated (author contacted via email, no response till date)	-Skills acquisition training - Literacy classes -Peer counselling	-Women did not return to their communities -Experiences of new life would be different to those that returned home; further research required
Turan et al, 2007	9 months	-Information on self-care and health maintenance provided	-Only 15 out of initial 64 in cohort showed up for follow up -Over half of them still incontinent; might have been reason for returning
Donnelly et al, 2015	1.5 years post last repair	-Transportation stipends, clothing and soap provided (not all received transportation stipend) -Post repair counselling	- Differences in post repair services for each woman

Alio et al, 2011	3months- 2years post repair (confirmed by email correspondence with first author)	<ul style="list-style-type: none"> -Skills acquisition trainings - Centre accompany women back to village on discharge - Centre educates community on fistula -Centre provides women seed grant to commence business - Peer counselling 	- Experiences were presented as plans of what they would do on return
Pope et al 2011	One month-13 years (mean 4.5years) Post fistula repair	<ul style="list-style-type: none"> -Preoperative counselling and directive on recuperation period at discharge -No post repair counselling after discharge -No reintegration assistance provided 	-Reintegration experience was drawn based on a data collection tool- Reintegration to Normal Living Index RNLI (Daneski et al, 2003) and interviews
Mohammed, 2007	Two- three months post rehabilitation	<ul style="list-style-type: none"> -Skills acquisition training -Literacy classes -Small enterprise management trainings -Graduation ceremony; family in attendance -Provision of interest free loan for business set up -Technical assistance and follow up of women in the community 	<ul style="list-style-type: none"> -Empirical data of women experiences not provided - Data used was program evaluation reports
Landry et al, 2013	Three months post repair	Services varied with country and facility; included	-Structured questionnaire was used to generate data on

		<ul style="list-style-type: none"> -Counselling; sexual and reproductive health -Psychological counselling -Support group activities -Skills acquisition trainings -Literacy training 	reintegration experience
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A total of eight articles discussed the reintegration services provided in the study sites (Table 2.3). In the studies sites of Mohammed (2007), Alio et al (2011), Landry et al (2013) and Gebresilase (2014) respectively psychological counselling and rehabilitative services were provided. These services include literacy classes, skills empowerment, provision of seed grants, follow up to the community and education on fistula in the community. Mohammed (2007) asserted that women that had been rehabilitated post repair were empowered socioeconomically and were owners of businesses in their communities. But in this study, the empirical data on the women’s personal experiences (for instance excerpts of quotes) were not provided. In the qualitative study by Alio et al (2011) lived reintegration experiences were not investigated, rather the women described their future plans. On the other hand, Landry et al (2013) the reintegration experiences were investigated using structured questionnaire only. This study was a large multicentre study that took place in five countries, but in each of the study sites the reintegration services varied. Such services could include one or some of the following; support group programs, sexual and reproductive health counselling, psychological counselling, skill empowerment and literacy classes. Differences in the services across the countries were not investigated. Furthermore, inclusion of a qualitative research would have provided a better insight into the women’s reintegration experiences. In the qualitative study by Gebresilase (2014) none of the rehabilitated women returned to their community after treatment.

Quality of Life after Fistula Repair

Generally, it is asserted that there is improved quality of life after surgery for women with successful repair who remain continent. This was a common view by majority of the articles reviewed that studied the quality of life after repair. Equally for those still incontinent there is improved quality of life (Nielsen et al., 2009, Yeakey, 2011). In the study by Umioyoho et al (2011) that used the WHOQOL BREF tool, they reported there was a general 90% increase in quality of life after repair in all the domains. The highest score recorded in the social domain, followed by that of the physical domain (Umioyoho et al, 2011). In the study by Nielsen et al (2009), there was a statistical significant improvement ($p= 0.001$) in quality of life after repair. In the study by Pope et al (2011) that did a comparative study among the groups of women, the group of women with repaired fistula had a higher score as compared to the control group that were women without fistula. Thus, they purported that the improved perceived quality of life was attributable to a successful repair and reintegration (Pope et al., 2011).

Furthermore, Pope et al (2011) suggested that after repair, perceived quality of life and ability to reintegrate improves with time. The improved control translated into "improved quality of life at home" for the women (Yeakey et al, 2011:1). Hence post repair, it is believed that women do not experience any more isolation and rejection from the community. Majority of the women were able to socialize freely and resume normal lives in their communities (Women's Dignity Project and EngenderHealth, 2006, Bangser, 2007). On the contrary, Muleta et al (2008) and Khisa and Nyamongo (2012) reported women still faced discriminations despite being continent, leading to further lowering of self-esteem; thereby hindering reintegration. In a similar vein, Gebresilase (2014) alleged that, in avoiding stigma, rejections and discriminations, the women did not reintegrate back into their family or communities after treatment. Such women felt better in their new lease of freedom, and autonomy in taking decisions, and caring for themselves in the city (Gebresilase, 2014). Similarly, Mselle et al (2012) described the lack of desire and unwillingness to return home after treatment or to remarry among the women. However, the women in the study by Mselle et al (2012) were mostly divorced. In the same vein, in the Gebresilase (2014) study all the women were divorced or separated from their husbands.

Marital, Reproductive and Sexual Life Experiences

The reproductive and sexual lives after reintegration were still in jeopardy by four of the studies (Browning and Menber, 2008, Khisa and Nyamongo, 2012, Mselle et al., 2012, Donnelly et al., 2015). However, Browning and Menber (2008) reported that six-months post repair, for the one third that had resumed sexual activity, 90% women had no pain. In study by Dolan et al (2008), sexual dysfunction symptoms reported were dryness in the vagina, dyspareunia and sex life disturbed by urinary symptoms. These symptoms were a little burdensome (Dolan et al., 2008). In the study by Nielsen et al (2009) at 21 months follow up, 71% had resumed sexual activity. However, in the study by El-Gazzaz et al (2010) 47% had resumed sexual activity at the follow up 45.8±39.2 months post repair. In this study, they used the “Female sexual function index” to measure the sexual function (El-Gazzaz et al, 2010, p.1761). The study reported that there was no significant differences between the women that were healed and those that were not healed in all the domains of desire, arousal, lubrication, orgasm, satisfaction and pain (El-Gazzaz et al., 2010). Generally, the fear of fistula recurring was reported to hinder sexual activity after repair (Muleta et al., 2008, Pope et al., 2011, Khisa and Nyamongo, 2012, Donnelly et al., 2015). However, fertility issues attributed to inability to engage in normal sexual functions and cultural expectations in child bearing were identified as reproductive health needs (Pope et al., 2011, Mselle et al., 2012, Donnelly et al., 2015).

The post-surgical abstinence from sex and loss of the uterus worsened marital stability for some women (Khisa and Nyamongo, 2012). This period of sexual abstinence varied from three months to one-year post repair (Yeakey, 2011, Khisa and Nyamongo, 2012, Donnelly et al., 2015). Three studies reported, women lacked the desire or interest in sex due to past fistula experience (Turan et al., 2007, Pope et al., 2011, Khisa and Nyamongo, 2012). On the other hand, Mselle (2012) believed even though some did not wish to remarry, they still desired to regain a normal reproductive ability and bear children. Nevertheless, generally the societal expectation of women’s worth is based on motherhood (Alio et al., 2011, Pope et al., 2011, Khisa and Nyamongo, 2012, Mselle et al., 2012). Khisa et al (2012) asserted that women’s’ hope in accessing repair was to be continent and have children. It is suggested that the desire for children particularly

for a son is greater with those that experienced loss of a child (Muleta et al., 2008, Mselle et al., 2012, Donnelly et al., 2015).

The prognosis of future delivery has not been fully demonstrated raising issues around fertility. Interestingly, Mohammed (2007) reported that between 1999 and 2006, among their rehabilitated 145 clients, there were 25 successful vagina deliveries, one death, but no fistula recurring. Only six out of these successful deliveries were in a facility (Mohammed, 2007). On the other hand, Turan et al (2007) noted none of the repaired women six to ten months post repairs, were pregnant even though they were sexually active. Browning and Menber (2008) in their six months follow up study, reported 35% had resumed sexual relationship and six of the women were pregnant. However, Browning and Menber (2008) suggested that six months was a short period to make conclusions on post repair fertility rates. Similarly, in 21 months follow up study in Ethiopia where there were five pregnancies, tragically there was one maternal death as a result of obstructed labour, two still births and one woman had fistula recurring (Nielsen et al., 2009). However, Donnelly (2015) in their study average period of one and half year post repair, reported four successful deliveries and two women struggling to conceive.

Socio-economic and Work Experiences

Across the studies a widely accepted desire for the women was to resume work and be self-sustaining after returning to their communities (Alio et al., 2011, Pope et al., 2011, Mselle et al., 2012, Donnelly et al., 2015). Mselle et al (2012) argued that economic self-sufficiency was closely linked to regaining dignity. However, the ability to resume normal work was not possible most times; for they were not physically strong to carry on the same economic activities or chores they were used to before (Donnelly et al., 2015). Hence the work engaged in post repair, usually would be less strenuous (Pope et al., 2011, Donnelly et al., 2015). Consequently, they become dependent on a heavily taxed family income for sustenance. Due to the economic constraints, their quality of life and reintegration is compromised (Mselle et al., 2012). This was however worse for those still incontinent (Donnelly et al., 2015). On the contrary, in the study by Pope et al (2011) even though women still had some physical challenges, majority resumed their farming

and home chores one-year post repair. For these women, their health challenge was not connected to their financial hardship but was a general phenomenon (Pope et al., 2011). It was believed that fear of fistula recurring because of physical exertion might be the reason behind some experiencing difficulties in resuming normal house chores and farming activities (Pope et al., 2011). Bangser (2007) however, alleged that a majority could perform their normal house chores after repair. Nevertheless, family and community support helped eased reintegration for some women (Pope et al., 2011). This includes assisting in getting chores done or establishing a business. Such supports also could be in form of provision of clothing, soaps and lotions. The same individuals that assisted in accessing treatment provided support in reintegration (Pope et al., 2011). The Women's Dignity Project and EngenderHealth (2006) believed that the positive family, neighbours and community support could be harnessed in community education and advocacy to stop stigma.

Living with Incontinence after Repair

The consequences of being incontinent after repair make reintegration more challenging. The studies show how women with a continuing leak still experience physical and psychological challenges (Women's Dignity Project and EngenderHealth, 2006, Bangser, 2007, Donnelly et al., 2015). There are women who suffer a breakdown of the fistula after being discharged continent (Browning and Menber, 2008). There were cases of women who had a recurrence after manual activity like tedious labour, straining, during sexual intercourse or while on a ride along a bad road (Browning and Menber, 2008). Fistula could also reoccur after another obstructed labour and delivery (Browning and Menber, 2008, Nielsen et al., 2009).

Unsuccessful repair cases could lead to the escalation of negative treatment in the community and feelings of frustration in the family (Women's Dignity Project and EngenderHealth, 2006, Khisa and Nyamongo, 2012). According to Khisa and Nyamongo (2012: 63) women in such conditions were considered "cursed" by the community. Such women were generally less likely to report improvement in their daily activities (Landry et al., 2013, Donnelly et al., 2015). On the contrary, in the UK study, residual incontinence had partial impact on the quality of life of women post fistula repair (Dolan

et al., 2008). Similarly, in the US study there were no significant differences in the quality of life and sexual function of women that were healed and those not healed (El-Gazzaz et al., 2010). However, the experiences of the women in the UK and US studies with relation to carrying on their normal lives and interactions were people were not evaluated. Therefore, in drawing a conclusion there is need to bear in mind that the contributory factors, aetiology of fistula and social effects of fistula in the developed countries are different from those in developing countries (Dolan et al., 2008).

2.3 Research Implications/Implications of Findings

The review has outlined the empirical evidence on the lives and experiences of women with obstetric fistula. Living with fistula has been seen to have multidimensional consequences in varying degrees on the woman, her family and the community. Hence the adoption of various coping strategies by the women. Earlier studies on women with fistula usually provided the description of young women or girls with no children who, after developing fistula, are ostracised and abandoned by their families because of the urine or faeces leakages. But in this review seven of the studies could argue that fistula could affect any woman; and not every one of them lost family support after fistula development (Women's Dignity Project and EngenderHealth, 2006, Bangser, 2007, Muleta et al., 2008, Umoiyoho et al., 2011b, Pope et al., 2011, Yeakey, 2011, Landry et al., 2013). Therefore, there is need to investigate whether there is an association between marital stability and presence of children for women with fistula. Furthermore, in the light of their treatment experiences where it was observed that women that received care had family support; there is also need to research further the determinants to access to fistula treatment and the role of family support.

Another area highlighted in the review was the women's treatment and care experiences. Successful surgical treatment contributed to an improved quality of life. In the review measuring the quality of life was achieved by using different validated tools, adopting a tool for measuring quality of life with women with obstetric fistula would be a laudable option allowing for a standardized assessment. Accessing treatment was not an easy task. It was observed that women that received treatment had family support; this seemed to buttress the ideation that women that access care are those that have

support to do so. Public health interventions on health promotion within the communities could be directed towards addressing the role of the family and community in assisting women with fistula in receiving care. The review also highlighted the dilemma in sexual and reproductive health issues despite successful repair; this calls for more research on improving future fertility for women after treatment. In the review, incontinence after successful repair was still an issue of concern. Failed repair cases are issues that require critical attention; support needs to be provided in the community to redress this. Furthermore, more research on irreparable cases is needed to address this.

The WHO guidelines emphasise that the objective of obstetric fistula repair is to ensure women regain their role and place within the community (de Bernis, 2007). In the review majority argued that rehabilitation program contributes to successful reintegration (Mohammad, 2007, Alio et al., 2011, Mselle et al., 2012, Landry et al., 2013, Donnelly et al., 2015). Others argue that women who are successfully repaired reintegrate without any assistance required (Nathan et al., 2009, Yeakey, 2011). In the review there was no comprehensive research that investigated the benefits of the program from the women' personal views. Therefore, a qualitative study to capture the nuances of the reintegration experiences would be useful in informing care management with respect to providing effective and efficient post repair rehabilitation services.

The lack of standardised treatment package in terms of the post repair rehabilitative services calls for a step up on research to investigate the benefits of the programs. Yeakey et al (2011) and Gebresilase (2014) however suggested that, accompanying repairs with psychological and social rehabilitation was only useful if the social condition that predisposes the women to fistula in the society was addressed. For fear of these challenges, hinders full reintegration back into their family and community life (Gebresilase, 2014); in this study none of the women returned to their community. As it was earlier observed, all the women were divorced and hence could be the reason behind the unwillingness to return to their community. Nevertheless, Landry et al (2013) believed community-based organization were better equipped in providing this post repair services. Therefore, further research as earlier suggested on the post repair rehabilitation services based on the women's perspective would be useful; it would be

worth exploring how such programs could contribute to reintegration of women as suggested by WHO guidelines for management of obstetric fistula (de Bernis, 2007).

Finally, the review has also established treatment and care does contribute positively to the lives of the women, family and community. But that closure of the fistula is just the beginning of the road to recovery (Wall and Arrowsmith, 2007). In ensuring successful fistula surgery there should be efforts to restore back to normal sexual functions, enhance fertility, heal psychological wounds and ensure a return to normal lives in the community (Wall and Arrowsmith, 2007). Addressing these issues can be better informed by properly designed research in these areas (Wall and Arrowsmith, 2007). Fistula care goes beyond fistula repair; holistic care approach would be required for the holistic recovery of the women (Donnelly et al., 2015). Emphasis should therefore be towards utilizing a multidisciplinary management care approach in facilities providing care (de Bernis, 2007). Strategies to address fistula management therefore need to shift from clinical care to a holistic care approach. Countries therefore need to develop policies with regards to entrenching holistic care approach into fistula management.

In view of these, the research gaps were identified as: were:

- The benefits of post repair rehabilitative psychosocial support to reintegration.
- Lack of in-depth empirical data on women's experiences of living with a fistula that covered their whole 'fistula journey' from formation through to their engagement with a reintegration programme.
- The coping mechanisms the women use
- The reintegration experiences of women with persisting incontinence
- The categories of treated women that reintegrate back to their communities
- The role of family and community support in reintegration
- The reproductive health and fertility issues after reintegration

2.4 Research Question and Objectives of Study

For this study, in view of the above gaps, the focus would be on women that had undergone the rehabilitation program and had returned to living in the community, therefore the **research question** is:

How do women attending a reintegration service describe their experience of living with fistula?

The **specific objectives** were to explore the following:

- The childbirth experiences that led to fistula formation
- The experiences of women while living with fistula
- The role of family and community while living with fistula and after treatment
- Women's health seeking behaviour and coping strategies after developing fistula
- The experiences of women after fistula repair
- What are their experiences of rehabilitative services

2.5 Conclusion to Chapter

This literature review chapter provided the details of the systematic search of literature on the experiences of women with obstetric fistula. The chapter assessed the methodological quality of the literature on the experiences of women with fistula. The findings of the literature were thematically analysed and discussed. The analysis of the findings provided evidential bases for further research. The review has brought to the fore the dearth of detailed research on the experiences of women who engaged with the rehabilitation services based on their perspectives, not only in Nigeria but generally. There is need to investigate these experiences to inform better management of women with fistula. Therefore, the study would consider gaining insights from treated women's experiences in a Northern setting in Nigeria. Based on the literature review and the research question that has been identified, therefore the next section is set up to discuss the methodology of the study.

CHAPTER THREE

METHODOLOGY

3.0 Introduction to Chapter

This chapter discusses the methodological issues surrounding the choice of the research method for the study. It examines the basis for the choice of qualitative research approach for the study. It discusses the philosophical and theoretical assumptions upon which the study is grounded. This chapter also looks at the typical characteristics of qualitative research, and the research choices made when conducting qualitative research. The chapter also looks at strategies taken to ensure trustworthiness in qualitative research and the ethical principles that govern research practice. Furthermore, it examines, in detail, the research approach for the study; narrative inquiry; its definition and the guiding theoretical framework that would be adopted for discussing the findings. The chapter also discusses narrative analysis methods and the use of narrative in illness experiences research. The ethical considerations for the study are also discussed.

3.1 Methodological Issues

3.1.1 Choice of Qualitative Research

The research question focuses on the experiences of women with obstetric fistula who had participated in reintegration service, therefore qualitative research would be the research choice. A research question that seeks to “provide an understanding of social behaviour” through the exploration of people’s account of their lives is answered through qualitative research (Avis, 2005: 4). Qualitative research is social research that focuses on interpretation and sense making attempts of people’s experiences of their world (Avis, 2005, Savin-Baden and Major, 2013). Qualitative health research is a method of investigating the health and illness experiences from the perspective of the persons involved (Morse, 2012). Therefore, the choice of qualitative research method is based on the fact that the study is focused on understanding women’s experiences. For according to Marshall and Rossman (2011), human activities can best be understood by the meanings individuals assign to them. Empirical evidence from the women’s

perspective as demonstrated in the literature review is sparse about their experiences across the whole spectrum of their fistula experience. Therefore, it is imperative to seek understanding of these by capturing the perspective of the women through qualitative methodology.

Qualitative research over the years has witnessed a wide acceptance in translational research; mainly due to the increasing emphasis on improved quality of care (Tripp-Reimer and Doebbeling, 2004). It highlights the human dimension in health care by focusing on views, experiences and behaviours of user and providers of care (Tripp-Reimer and Doebbeling, 2004). Consequently, qualitative research is very useful in exploring complex issues connected to improving quality of care and health system changes (Tripp-Reimer and Doebbeling, 2004). Stephens (2009) opined that even though qualitative methods had contributed significantly to international public health research, its use in public health research from developing countries were limited.

The unique characteristics of qualitative research that makes it appropriate for the research question include the following:

Qualitative research concentrates on the “emic perspective” of persons including their views and what meanings or interpretations they give to it (Savin-Baden and Major, 2013: 12). Hence can be used to gain understanding of people, culture and other experiences, rather than analysing variables relationships or test causal effects relationships as demonstrated in a quantitative study (Creswell, 2007, Savin-Baden and Major, 2013). Morse (2012: 52) refers to this as the “humanizing” aspect of qualitative health research wherein an inquiry goes “below the surface” to explore unquantifiable phenomenon; for instance, to equal out people using statistical means, rubs out the “uniqueness of individuals” (Creswell, 2007: 40). Therefore qualitative approach gives a voice to the participants in health research, for it gives the opportunity to convey the meaning of illness from the sick person’s perspective (Morse, 2012). According to Creswell (2007) it allows participants to tell their stories irrespective of expectations or what literature presents on the issue.

Furthermore, qualitative research allows the researcher to acknowledge the existence of “multiple constructed realities” (Savin-Baden and Major, 2013: 13). The “truth” is not

waiting to be discovered instead the researcher provides a description of their understanding and how the realization of the realities of their participants came about (Savin-Baden and Major, 2013: 13). This is unachievable with quantitative research; the complexity of the research question requires exploring the interactions among persons and their environment, and paying attention to issues that might cause differences (Creswell, 2007). This according to Creswell (2007: 39) is a “holistic account”; wherein complex pictures with multifaceted interactions are presented in relation to an issue under investigation. Additionally, qualitative research takes places in the natural setting of participants (Creswell, 2007, Savin-Baden and Major, 2013). This allows for contextual understanding which is critical for understanding the meanings participants are communicating (Savin-Baden and Major, 2013); for people cannot be separated from the context in which they present their accounts (Creswell, 2007).

Factors that contribute to the development of fistula have been linked with issues that border on socio cultural and behavioural factors, as such the experiences of living with fistula would be assumed to be influenced by these factors (Roush et al., 2012, Wall, 2012a). In exploring this issue therefore, qualitative research would allow an unbiased investigation of the inquiry of interest.

3.1.2 Philosophical Paradigms and Theoretical Assumptions of the Study

Qualitative research is guided by numerous philosophical schools of thoughts or traditions (Savin-Baden and Major, 2013). These philosophical beliefs and paradigms evolved over the years, the product of numerous debates in the social sciences (Savin-Baden and Major, 2013). The crux of these debates were the claim to universality and validity by the philosophy of science, which challenged the objectivity of social sciences (Williams, 1996, Yar, 2005). The major philosophical schools of thought of qualitative research are the post-positivism, post modernism, constructivism, social constructionism, advocacy/participatory and pragmatism (Creswell, 2007, Savin-Baden and Major, 2013). Others are critical social theory, feminism and queer theory (Creswell, 2007). These schools of thought differ in their views of realities and how knowledge is construed in qualitative research (Creswell, 2007, Savin-Baden and Major, 2013).

The choice of a philosophical assumption is the commencing point of qualitative research, it influences the choice of method and eventually the success of the study (Savin-Baden and Major, 2013). There are various paradigms or worldviews that influence the conduct of qualitative research (Creswell, 2007). These paradigms were outcomes of debates that developed over the years from criticism of the failure of positivism in providing an understanding into human actions in the social sciences (Rapport, 2004). Furthermore the choice of qualitative research by a researcher is based on certain philosophical assumptions (Mason, 2002, Creswell, 2007). These assumptions are the stance of the researcher towards the “nature of the reality” or the phenomenon to be studied, known as the ontology (Creswell, 2007: 16). Another philosophical assumption is the epistemology which refers to what the evidence of the social reality is, that is how the researcher generates the data (Mason, 2002, Creswell, 2007). Generally most qualitative research approaches have a common ontological view of constructionism (Creswell, 2007); for qualitative research investigates the mode in which individuals make sense of their experiences and ideas (Savin-Baden and Major, 2013).

For this study considering the research question, the paradigm of choice is social constructionism/interpretivism. Social constructionism is based on the fact that individuals construct social meanings of their world (Avis, 2005, Creswell, 2007). However, these meanings are numerous and diverse resulting from interactions with other social actors, and “through historical and cultural norms” that directs the individuals’ lives (Creswell, 2007: 21). The goal of research therefore is to depend on the participant’s perspectives on the issue (Creswell, 2007).

3.1.3 Research Choices in Qualitative Inquiry

Designing and implementing qualitative research involves making a number of critical choices (Savin-Baden and Major, 2013). Savin-Baden and Major (2013: 44) describes these choices using the “qualitative researcher’s wheel of research choices”. The wheel is divided into five rings, which is further subdivided into six segments. The first ring on the wheel is the section on choosing a research paradigm. The first ring influences the second ring as well as the whole research process. The second ring is the section on

choosing the research phenomenon, which could be individual, group, concept, event, structure, and artefacts. This ring equally influences subsequent decisions. The third ring represents the choice of qualitative approach which could be grounded theory, narrative, ethnography, phenomenology, action research or pragmatic qualitative research. This choice is influenced by both the choices of paradigm and research phenomenon; consequently, it affects the other subsequent choices. The fourth ring is the section on choosing a data generation method. The preceding and subsequent ring influences this ring. There are different growing numbers of ways data can be generated in qualitative research. Flick (2014: 293-295) describes methods of generating verbal data and “data beyond talk”. Verbal data are generated through methods that require participants to speak about their experiences; through interviews, storytelling, and focus group discussions (Nettleton, 1995). “Data beyond talk” on the other hand are visual data, involving observation and ethnography or, visual data like documents, pictures, films and videos (Flick, 2014). The final and fifth ring is the analytical choice (Savin-Baden and Major, 2013). The analytical strategy is determined by the ontological and epistemological positions of the selected methodological approach (Mason, 2002). In the choice of an appropriate data analysis method Flick (2014) suggested the research question, study goals and the data collected would determine the method of analysis.

In the qualitative research choices wheel, all the choices are interconnected; hence the wheel is dynamic allowing for combination of choices (Savin-Baden and Major, 2013). However in combining paradigm, phenomenon, approaches, data generation method, and analytical methods, certain combinations fit more naturally than others (Savin-Baden and Major, 2013). Participant sampling is another critical aspect of research choices in qualitative study. It requires identifying who might provide the best answer to the research question (Savin-Baden and Major, 2013). Generally there are two types of sampling approaches in qualitative research; theoretical sampling and purposive sampling (Curtis et al., 2000, Savin-Baden and Major, 2013). Theoretical sampling is used to generate theory and most often associated with grounded theory studies (Curtis et al., 2000). On the other hand in purposive sampling the participants and sites are selected because they can purposefully provide an understanding of the research question and the phenomenon under investigation (Creswell, 2007). Both methods

increases the scope of data and probability that the full range of multiple realities would be uncovered (Lincoln and Guba, 1985). However, based on the research approach researchers need to determine whether the sampling will provide the required information (Creswell, 2007).

The six key features of sampling identified by Curtis et al (2000: 1003) based on Miles (1994) checklist consist of: (1) Applicability to the conceptual framework and research question. (2) Suitability to provide detailed information on the phenomenon of interest. (3) Ability to augment the 'generalizability' of the findings; (4) Provision of a convincing description of the experience. (5) Sampling. (6) Ethical and feasibility procedures (Kleinman and Seemam, 2003). A range of purposeful sampling methods have been developed but it is important that the choice should be justifiable and based on the research topic and question (Savin-Baden and Major, 2013). Equally sampling can change during the process; hence researchers need to be flexible. However plans should be in place on sampling strategy (Creswell, 2007). For instance, the researcher might begin with a theoretical sampling and proceed to "snowball", interviewing persons identified from the initial sample (Marshall and Rossman, 2011: 112). In qualitative research, sampling continues until data saturation point is reached; the researcher stops collecting data when no new information or observation is seen (Savin-Baden and Major, 2013). However, this notion does not always hold true particularly in constructivism approaches like in narrative inquiry or participatory action or art based inquiry where there are always new things to learn (Savin-Baden and Major, 2013).

Sample size is another important consideration in the sampling strategy of qualitative research (Creswell, 2007). According to Creswell (2007) the general principle is not to study few sites or participants but collect adequate details on sites or participants studied. Furthermore, there are size variations based on the different five research approaches (Creswell, 2007). Even though funding and time constraints may influence sample size, the purpose of the research is the most important consideration in determining sample size (Marshall and Rossman, 2011). Savin-Baden and Major (2013) on the other hand, based sample size on providing answers to the following questions; what the research approach is, what is required to be accomplished, what kind of

sampling is required, what data detail is to be collected and how many of the individuals have the required characteristics of interest?

3.1.4 Ensuring Quality in Qualitative Research

Various terms have been developed and debated upon as to described the most appropriate term to describe quality in qualitative research (Savin-Baden and Major, 2013). These debates evolved from earlier debates on the inappropriateness of demonstrating quality of qualitative research using the traditional validity and reliability criteria (Savin-Baden and Major, 2013). Trustworthiness/ rigor in qualitative terms is synonymous to reliability /validity in quantitative terms (Thomas and Magilvy, 2011). Rigor therefore refers to ways of establishing trust or confidence in the findings of a research (Thomas and Magilvy, 2011). Researchers are encouraged to clearly adapt a strategy applicable to their study from the onset and throughout the research process (Savin-Baden and Major, 2013). Various approaches and concepts have been brought forward in line with the author's world view to establish quality in qualitative research (Creswell, 2007, Savin-Baden and Major, 2013).

In establishing trustworthiness in qualitative research, Lincoln and Guba (1985: 300) proposed a four-point criterion of "credibility, transferability, dependability and confirmability".

Credibility- study should be convincing, the researcher should be able to demonstrate the participants' "reality". Credibility is analogous to internal validity in a quantitative research (Thomas and Magilvy, 2011). It is that feature that permits others to understand the experiences studied through the interpretations of the experiences of the participants (Thomas and Magilvy, 2011). Koch (1994: 977) suggested that the reflection of the researcher's "self-awareness" process captured in a journal is an important part of establishing credibility. The following five strategies suggested by Lincoln and Guba (1985) can be used to improve credible findings:

1. Activities that improves the likelihood of production of credible findings include the following: staying long on the field, continual observation and triangulation (Lincoln and Guba, 1985). Staying long on the field helps the researcher to detect

misrepresentations of accounts, it also provides opportunity to build trust and rapport with participants (Lincoln and Guba, 1985). Continual observation provides a depth to the inquiry, for it allows the researcher to identify characteristics and features more relevant to the focus of inquiry (Lincoln and Guba, 1985). On the other hand, triangulation improves the possibility that findings and explanations are more credible (Lincoln and Guba, 1985). Triangulation is the process of bringing more than a single data source to bear on a single issue (Marshall and Rossman, 2011). It maybe of data, researcher, theory, method and analysis (Savin-Baden and Major, 2013). The diverse data sources in triangulation helps to provide a broader understanding of research question (Savin-Baden and Major, 2013).

2. Providing an external check on the research process through peer review of the different phases of the study (Lincoln and Guba, 1985). This process help to improve credibility by allowing an expert assess the accuracy; checking that finding and meanings are data supported (Savin-Baden and Major, 2013). It also helps to test out hypothesis, develop emergent scheme and allow for catharsis (Lincoln and Guba, 1985). The “debriefers” should however be someone with vast knowledge in the area of study and the methodological subject matter (Lincoln and Guba, 1985: 308).
3. Allow emerging hypothesis to be refined- using negative case analysis (Lincoln and Guba, 1985). In negative case analysis, a researcher during the data analysis critically identify data elements that do not support or contradicts findings (Savin-Baden and Major, 2013). The researcher refines analysis to account for all the known cases not leaving out any (Lincoln and Guba, 1985).
4. Checking preliminary finding against raw data- through “referential adequacy”(Lincoln and Guba, 1985: 313); portions of the raw data would be archived for easy recall when tentative findings have been obtained (Lincoln and Guba, 1985).
5. Direct checking of findings from the field, through “member checking” (Lincoln and Guba, 1985: 314); This involves participants feedbacks; allows the

participant voice to be heard and to correct any misinterpretation by the researcher (Lincoln and Guba, 1985, Savin-Baden and Major, 2013).

Transferability- this concept refers to how generalizable the findings of the research are. Generalizability entails the extent to which research findings can be extended wider, rather than claiming it was peculiar and specific (Mason, 2002). This undoubtedly is an issue in qualitative research; the contextual nature of qualitative research gives its findings a “specific expressiveness” (Flick, 2014: 495). Therefore, attempts in generalizing would require giving up the context link to ascertain whether the findings are applicable independent of the specific contexts (Flick, 2014). Lincoln and Guba (1985) argued that it was impossible to achieve generalizability in the true sense for qualitative research, but the researcher could provide a rich description to enable potential applicators to make informed judgement on the applicability of the findings. Thomas and Magilvy (2011) alleged that rich description through provision of description of participants’ demographic and geographic confines of study can improve transferability. Triangulation of multiple sources of data can also enhance the generalizability (Marshall and Rossman, 2011); a study designed with “multiple cases, multiple informants” or greater than one data generation method can significantly strengthen the study’s applicability to other settings (Marshall and Rossman, 2011: 253).

Dependability- this is connected with the reliability in quantitative study; when a different researcher can track the decision trail of the researcher (Thomas and Magilvy, 2011). Reliability entails the accuracy of the research procedures, how consistently and precisely do they produce data, how can this be optimized? (Mason, 2002). The reliability notion is a positivist ideology of an unchanging world where research can be logical and replicable (Marshall and Rossman, 2011). However, this notion is at variance with the qualitative interpretation of the social world. The social world is always being constructed, hence replication is an issue. Addressing this would require ensuring methodical accuracy in documenting and transcribing data details, with frequent cross checking of data and interpretations (Roberts and Priest, 2010). Flick (2014) opined that audit trail can improve methodical dependability. Strategies to improve reliability could include involving peer participation in data analysis, provision of detailed research methods or repeating the study step-by-step to check if similar results are obtained or

initial findings are enhanced (Thomas and Magilvy, 2011). This does not refer to replication, for this is not feasible in qualitative research (Thomas and Magilvy, 2011).

Confirmability- the term is usually associated to reliability and objectivity in quantitative research (Jensen, 2008). It is used to describe the additional processes involved in establishing the truthfulness of the assertions of the study (Jensen, 2008). In qualitative research it is concerned with providing evidence that the participants' perception is the root of the interpretation of the data and also that the data analysis, findings and conclusions are verifiable and reflective of participant's views (Jensen, 2008). The techniques used to determine credibility, dependability and transferability together constitute the core for ascertaining confirmability (Lincoln and Guba, 1985). This can be achieved by using an audit trail that serves as a sign post showing research choices and influences throughout the whole research process (Lincoln and Guba, 1985, Koch, 1994).

3.1.5 Ethical Principles in Qualitative Research

Ethical issues are of paramount importance in qualitative researches. Qualitative inquiry is focused on understanding, exploring and describing people and their geographical environment (Orb et al., 2001). The relational nature of qualitative inquiry, make ethical obligations a necessity (Savin-Baden and Major, 2013). The research process has the capacity to create tension between the research goal of generalizing for the benefit of others and the rights to confidentiality of participants (Orb et al., 2001). Ethical principles seek to protect the participants (Orb et al., 2001). For Davies and Dodd (2002: 281), ethics means "truthfulness, openness, honesty, respectfulness, carefulness and constant attentiveness" hence should not be treated as just a procedural rule for research. Consequently ethics should be an integral part of rigor in qualitative research (Davies and Dodd, 2002).

Health research ethics involve relevance of the research design, methodology, funding sources and actions in data reporting (Orb et al., 2001). Historical precedents of violation of human rights in the bid of scientific research necessitated protection of human participants in research (Orb et al., 2001). In health, research ethics are governed by principles developed by Schnell and Heintz (2006), cited in Flick (2014) and the researcher is expected to be able to do the following:

- Justify the research
- Explain the aim of the research and circumstances of the participants
- Provide detailed description of the methodology of the study
- Predict the potential ethical positive or negative consequences
- Assess potential violations and harms that might arise during the study
- Take steps to prevent identified violations and harm
- Must not make bogus statements about benefits of study
- Respect data protection regulations

The codes of ethics developed by Beauchamp and Childress (2001) of “autonomy, beneficence, non-maleficence, justice and autonomy” form the fundamental principles that govern health research ethical guidelines (Lawrence, 2007: 35):

Autonomy- the participant’s value and decisions should be respected (Flick, 2014); in research this principle is honoured by informed consent in which participants are provided the right amount of information (Kvale, 1996). Furthermore, participants are allowed a free hand to make a choice to agree or refuse to participate in the research (Orb et al., 2000, Lawrence, 2007). Ethical issues can sometimes arise in interviews on experiences that were sensitive and painful (Orb et al, 2001). For instance, participants could become distressed during interviews of painful experiences of violence (Orb et al, 2001). The researcher is expected to be aware and has the moral obligation to refer participants for counselling or ensure they have regained proper control of the situation (Orb et al, 2001).

Beneficence and non-maleficence: Beneficence- research should be of positive and specific benefit to the participants (Flick, 2014). Non-maleficence- research should not harm the participants (Flick, 2014). This involves the disclosure of any potential risk to participants in a clinical research (Lawrence, 2007). In qualitative research, this relates to issues surrounding confidentiality. The researcher has the moral obligation not to reveal the identities of the participants; this can be achieved through use of pseudonyms

(Orb et al, 2001). Confidentiality also involves data management; participants' information are shared in line with the permission granted (Savin-Baden and Major, 2013). In addition to ensuring privacy, proper data storage is carried out to limit unauthorised access (Savin-Baden and Major, 2013).

Justice-this refers to ensuring everyone is treated equally and with fairness (Orb et al., 2001). Avoiding over exploitation and abuse of participants; in qualitative research this involves recognising participants' vulnerability and their contributions to the research (Orb et al., 2001).

These codes of ethics form the core of ethical principles governing research and the researcher (Orb et al., 2001). The principles cannot guarantee ethical research, but it provides an understanding that ethical responsibility is a continuous process (Orb et al., 2001). Ethical dilemmas however sometimes exists in the application of the ethical principles during the research process (Orb et al., 2001, Creswell, 2007). According to Davies and Dodd (2002) it's application should be progressive, not to be overlooked but flexible, contextual and responsive to change.

3.1.6 Historical Precedent and Choice of Approach

Historically, various qualitative research approaches have been developed, and are organized into groups according to specialities (Creswell, 2007, Marshall and Rossman, 2011). Five qualitative approaches that are usually used by health, social and behavioural studies are; narrative research/inquiry, grounded theory, phenomenology, ethnography and case study (Creswell, 2007). According to Creswell (2007) each approach deals with the collection and analysis of data differently. In line with the underlying philosophical assumptions of the study, which is social constructivism, the research goal would be to depend on the participants' view of their fistula experience.

The social and cultural contextual undertone of this study therefore calls for a research method that can traverse through the complexities and present an informative but context specific and valuable account (Morse, 2012). Hence the choice of narrative inquiry as an appropriate approach, to conduct the study on the experiences of women with obstetric fistula in Nigeria. The women with obstetric fistula have a story to tell;

their ordeal began as a series of events with the interplay of other social actors (Wall, 2006). Furthermore, storytelling is a recognized cultural practice in Africa (Banks-Wallace, 1998). It has been used for passing of moral instructions and information, preservation of culture, and strengthening of community and family relationships (Banks-Wallace, 1998). Story telling in Africa, was also one of the significant way of historical and cultural preservation by different groups (Banks-Wallace, 1998). Oral tradition is another important aspect of African history (Vansina, 1971). Oral tradition is a process of passing messages by word of mouth from the past to the present (Vansina, 1985). This could be spoken, sung or sounds produced by musical instruments only (Vansina, 1985). African history developed as it is known today, majorly via oral tradition; in pre-colonial Africa, all major “political, legal, social and religious texts” were orally communicated (Vasina, 1971: 443). Identification of these factors is important in selection of a culturally appropriate methodology in an international setting for research (Stephens, 2009). Consequently, this makes the choice of narrative inquiry a feasible study approach within this context. Furthermore, the cultural context would be drawn upon in describing and giving meaning to the study (Stephens, 2009).

3.2 Narrative Inquiry Approach

3.2.1 Defining Narrative Inquiry

Narrative inquiry is a method of study that concentrates on stories individuals tell about themselves (Creswell, 2007). The data collection process involves in- depth interviews that “gather, analyse and interpret stories people tell about their lives” (Marshall, 2011: 151). Narrative inquiry is grounded on the notion that people “live storied lives”; the telling helps them to understand and subsequently generate meaning to it. Similarly, narrative inquiry has the ability to depict the beginning, central and end, when describing a change (Steinmetz, 1992); it illustrates a serial pattern of events that happens over time with a “cause and effect relationship”(Steinmetz, 1992).

Narrative inquiry involves an inclination towards the context of stories told; individual stories are located within the “participants’ personal experiences”, “their culture” and “their historical context” (Creswell, 2007: 56). Stories helps to identify non-conscious intentions, revealing individual’s social, personal and cultural interpretations (Orbuch,

1997). It involves active collaboration with the participants to “re-story” their stories into a format that is logical (Creswell, 2007: 56). Sources of material listed by Riessman (2008) for narrative inquiry include observation, interviews, memoirs, diaries, biography/autobiography, archival documents, photographs and art works (Bleakley, 2005, Riessman, 2008). However, Riessman (2008) argues that even though narrative is everywhere not all texts and talks are narratives. In the studying of lived in human experience in narrative inquiry, this provides ways of transforming the experiences for the participants and others (Clandinin, 2007). Lawler (2002) argued that narratives are used by people to interpret their social world, their position in it and to establish their identity. Participants would most often provide narratives of experiences that occurred in their lives where “ideal and real, self and society” were breached (Riessman, 1993: 219). Narratives are useful for research because it can expose truths on human experiences (Riessman, 2008).

Theoretical Development of Narrative Inquiry

The development of the theory of the narrative research are linked to scholars like Dewey, Bruner and Geertz in the social sciences (Savin-Baden and Major, 2013). The most influential philosophical foundation of narrative inquiry that would be discussed here is that of John Dewey (Clandinin and Caine, 2008). This theory is based on the criteria of experience and continuity (Clandinin and Connelly, 2000). Dewey believed experience occurs narratively. Furthermore Dewey argued that, experience is social and personal; as persons are known as individuals (personal) and in how they relate to others (social) (Clandinin and Connelly, 2000). Again, in relation to continuity, Dewey believed that experiences develop out of other experiences and experiences lead to further experiences. Hence for personal and social experiences, it is a back and forth swing on the past, present and future (Clandinin and Connelly, 2000).

Narrative inquiry is teamwork between the participants and researcher over a certain period, in a location or series of locations and in social relations with milieu (Clandinin and Connelly, 2000). Accordingly, therefore, research is conducted within the “three-dimensional narrative inquiry space” of continuity, situation and interaction (Clandinin and Connelly, 2000: 54, Clandinin and Caine, 2008). These “three dimensional narrative

inquiry space” is the direction or avenues to carry out a narrative inquiry (Clandinin and Connelly, 2000); they provide an understanding to the story. The “personal and social” experience are the interaction, the “past, present and future” are the continuity, while the “place” is the situation (Clandinin and Connelly, 2000: 54).

Addressing the Challenges of Narrative Inquiry

Narrative inquiry can be a challenging method of approach to use (Savin-Baden and Major, 2013). A large amount of information about the participants is collected that would require a good contextual understanding of the lives of the individuals (Creswell, 2007). It would also require the ability to identify in the midst of the materials the right story that captures the experiences (Creswell, 2007). Again there might be difficulties in interpretation of story; the presentation of the story told by the participant as a retold story (Savin-Baden and Major, 2013). This also borders on the issue of “story ownership”(Savin-Baden and Major, 2013: 241); who owns the story and how it should be told (Creswell, 2007, Savin-Baden and Major, 2013). To address these challenges, active collaboration would be pursued from the onset of the research process (Creswell, 2007). This would involve discussions and negotiations with the participants in the interpretation and presentation of the story (Creswell, 2007, Savin-Baden and Major, 2013).

Another challenge faced by narrative inquiry is proving the validity of the findings. Narratives are confounded with constantly changing social debates and power relations (Riessman, 1993). Furthermore, narratives by individuals cannot be assumed to remain consistent with different settings (Riessman, 1993). This would be addressed by working within the situated perspective; following the methods designed and guided by the ethical requirements to present the story to establish trustworthiness (Riessman, 2008); this would be attended to by ensuring a coherent and persuasive presentation guided by theory is the outcome of the study (Riessman, 2008).

The influence of the researcher’s personal and political inclinations and background can also influence the shaping of the story (Creswell, 2007). This would be addressed as a process of author’s reflexivity within the study, this in turn strengthens validity (Riessman, 2008). Working with data that would be translated interviews can also be

an issue as the case would be for this study. Diverse meanings across languages, can lead to arduous “interpretive decisions” (Riessman, 2008: 42). According to Temple and Young (2004) when the researcher and the translators are different individuals, another layer is introduced into the construction of data. To address this, Riessman (2008) suggested that the translator should be an active participant in the construction of the data. Therefore, in this study, the translator would play an active role in the data construction.

3.2.2 Narrative Theoretical Framework

Introduction

Narrative as data is a story that has been told in a medium (Bal, 1997). Applying a theory is essential to gain an understanding, how to analyse and assess the narrative (Bal, 1997). The building process theory for narratives of organizational processes has been applied to provide explanations to stories in which relationships between events are required (Pentland, 1999). The theory provides significant insight into the issues; this it does by illustrating the underlying process that led to the events (Pentland, 1999). Consequently to consider the narrative as a data would require highlighting the distinctive features of the text (Pentland, 1999). These features play critical role in the text development and they also explain the relationship between narrative, the process and explanation (Pentland, 1999). Therefore, in line with the research question, the building process theory would be used to analyse the underlying event surrounding the women’s experiences of fistula. It would help to identify what questions to ask as the event unfolds during the analysis of data.

Features in Narrative as Data

1. Sequence

Narratives usually should have a starting point, middle and end which is presented as a sequence over time even for fragmented stories (Pentland, 1999). The events sequence are part of the “deep structure of a story”, which is the “fabula” (Pentland, 1999: 712); fabula is the series of logical and chronological shaped events experienced by the actors in this case the participants (Bal, 1997). In the ordering of a story, the events are

arranged sequentially which can be different from “chronological sequence” (Bal, 1997: 8). This Bold (2012) identified as the temporality feature of a narrative. This feature is an important part of any research on social circumstances, since change is unavoidable (Bold, 2012c).

2. Focal Actors/Actor

Narratives are usually about actors or character- somebody or something. Which could be a person, group, organizations or projects (Pentland, 1999, Bal, 1997). They are “agents that perform actions” (Bal, 1997: 5). To understand the role layout and social network within which a plot process of a story, the characters have to be identified (Pentland, 1999). Unveiling the identities of who performs an act is important because each role differs (Pentland, 1999). In this research the fistula survivors are the focal actors, while their husband, family and the community are the other actors.

3. Identifiable Narrative Voice

Within the narrative is the narrator; who does the narrating (Bal, 1997); the identifiable voice is the voice that echoes a specific perspective (Pentland, 1999) in this case the narrator is also the actor (Bal, 1997). According to Frank (1995: 140) only the ill person can tell the story of their illness; for they are the “living testimony”, having lived in it or are living it. In this study the identifiable narrative voice is the fistula survivor; the woman/women.

4. Evaluative Context

A narrative above other data form can provide an insight into the cultural values of a group (Pentland, 1999). Thus the evaluation of culture provides a basis for the morals behind the narrative of a culture (Pentland, 1999). It allows the researcher to examine modes in which actions are guided by culture in addition to other issues (Pentland, 1999). The cultural connotation to obstetric fistula development is a topic that has been studied by various authors, hence would serve as a background when evaluating the actions of the participants.

5. Other Indicators of Context

There are usually a number of other indicators that help to identify necessary concepts (Pentland, 1999). According to Barthes (1975) narratives are more than simple events, but include among others diverse textual mechanisms that signify time, venue, features of the character and features of the context. These indicators serve to provide crucial information for the interpretation of events and not to develop the story (Pentland, 1999). Hence in this study the setting, the demographic characteristic of the participants, would be considered as a part of the evaluative procedure.

3.2.3 Understanding Building Process Theory of Narrative

Narratives are better understood as process theory, since they are personified by sequence and time (Pentland, 1999). According to Bal (1997) every specific narrative involves an explanation of processes, which distinguishes it from other narratives. Barthes (1975) on the other hand describes narrative as a sequence of events. Process theory therefore seeks to provide an explanation to stories (Pentland, 1999). Abbott (1992) argues that presenting narrative as a process can be used as an alternate concept in sociological research in which the centre of analysis is based on procedures, processes, performances and agents. Abbott (1990) recognizes three sets of questions the analysis addresses; firstly, the existence and grouping of sequential forms; secondly, the antecedents of the patterns; lastly the consequences of the patterns. Pentland (1999) opines that the antecedent and consequences, and the sequential patterns provide an explanation to the processes.

Antecedents and Consequences

These imply looking for associations in the conditions that triggered the process and in the outcomes of the process (Pentland, 1999). However, Abbot (1992) argues against its applicability; critically referring to it as stories that are ad hoc fallacy, created to provide an explanation for an observed association amongst variables. On the other hand, Sutton and Staw (1995) believe that, merely listing the antecedent does not make for a theoretical argument; an explanation is necessary on why certain variables are expected to be powerful predictors. It is the responsibility of the researcher to provide the missing

events, for theory can only exist with explanation (Sutton and Staw, 1995). For instance, Lawrence (1997: 20) adjures that in analysing “the relationship between demographic predictors in organizational outcomes”, it is crucial to develop a persuasive theory that explains how and under what conditions these structures operate.

Sequential Patterns

These patterns are critical in providing explanation to events; they describe the chain of events that connects the antecedents to the consequences (Einhorn and Hogarth, 1986). The standard of ordering in narratives are hypothetical and it is mainly to allow a description to the way data is generated in a story (Bal, 1997). The events are ordered in a sequence which may differ from the chronological sequence (Bal, 1997). Although for the sake of ease, processes are usually described as fixed sequence of, $A \rightarrow B \rightarrow C$ (Pentland, 1999). This unfortunately could contribute to inaccuracy, as actual processes cannot be portrayed as a lone sequence or narrative (Pentland, 1999). Despite how the choice in making a compromise among ease, accuracy and generality is made, the rationality of explanation is similar (Pentland, 1999). Describing the events that links them, explains the association between antecedents and consequences (Einhorn and Hogarth, 1986). However, relating the pattern of events does not solely explain the causal processes that produced the patterns. According to Abbot (1992), explanation can be obtained by an insight into the generating mechanism that propels the process. This would require searching for the “deep structures” of the “generating mechanisms” (Pentland, 1999: 719). The levels of the narrative structure provide the explanation as is presented below.

3.2.4 Levels of Narrative Structure

Introduction of Levels of Narrative Structure

In moving from the “surface level to deeper levels in a story”, applying the narrative theory tools can provide significant guidance (Pentland, 1999: 719). The deepest level is the “generating mechanism” that propels the process. It is the level of the underlying structure of the story (Pentland, 1999). Normally this level is beyond the scope of the

average narrative theory; that is concerned with ways particular events are narrated rather than actually providing an explanation to why the events occur (Pentland, 1999).

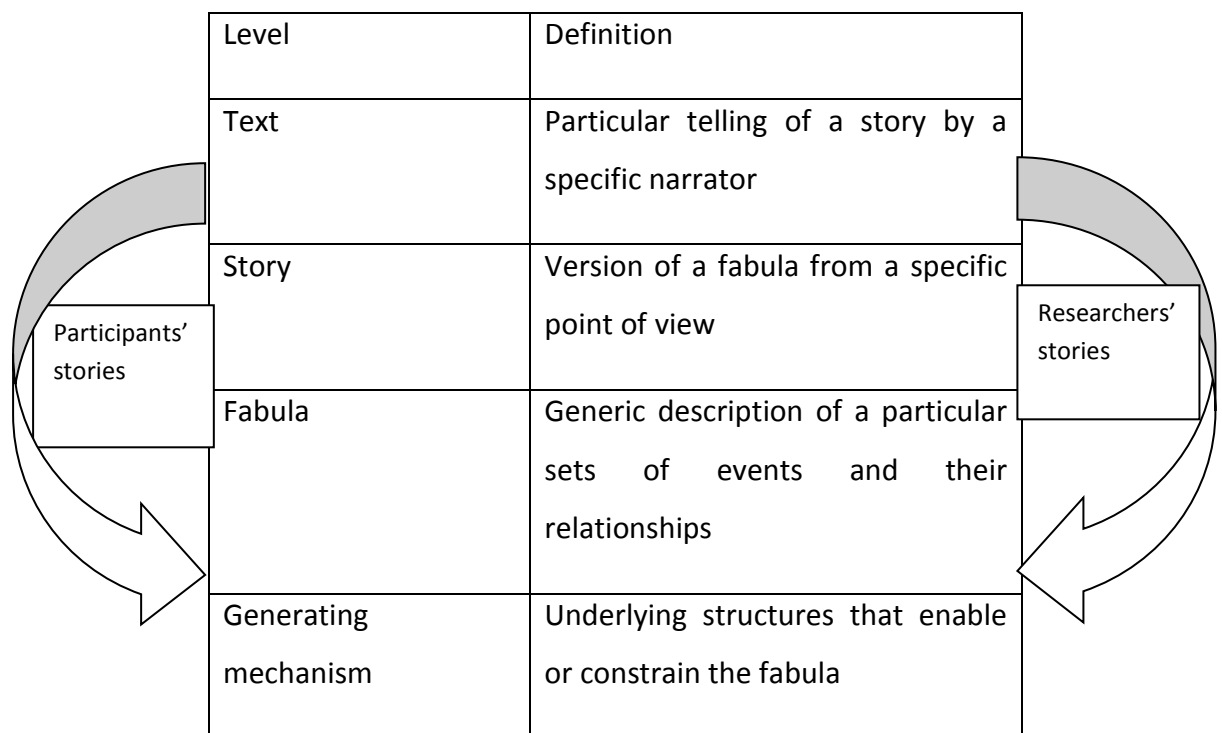


Figure 6: "Levels of structure in narrative"

Adapted from: Building theory with narrative: from description to explanation (Pentland, 1999)

Hence the narrative theory begins at the “fabula” level (Pentland, 1999). Bal (1997: 5) defined fabula as a “series of logically and chronologically” connected events, “caused or experienced by actors”. The fabula encrypts an objective account of the principal events and characters required to exclusively identify a specific story (Pentland, 1999). The fabula’s generative mechanism allows a single underlying event structure to be reproduced in several separate texts, renditions, books or films (Pentland, 1999). The elements of a fabula are the actors, events, time and location (Bal, 1997). However there are numerous processes involved in organizing elements into a narrative (Bal, 1997). According to Bal (1999: 7) the events are sequential, differing from chronological order; amount of time is based on the time each of the elements use in the fabula; actors are “individualized” into characters; the locations are specific places.

The next level after this is the story “level”; referred to by Bal (1997: 8) as the “point of view” or “focalization”. This is the point at which the events in the fabula are perceived and told (Bal, 1997, Pentland, 1999). It is the level at which the “narrative voice and the evaluative context” assume a narrative form (Pentland, 1999: 720). Naturally, the focalization process introduces subjectivity into the process (Bal, 1997, Pentland, 1999). Focalization thus reduces objectivity, and it is a threat to validity; for it is a selective and value – laden recount of the events (Pentland, 1999). For instance, researchers tend to focalize participants, when they choose what to evaluate and report (Pentland, 1999). In the final level at the surface is the text of the narrative recounted (Pentland, 1999). It is the level at which participant give their accounts, making a sense of their actions and others (Pentland, 1999). Equally this is the data collection level (Pentland, 1999).

This process theory according to Pentland (1999) is important because it helps the researcher to pay attention beyond the data on the text level; equally the researcher would pay attention to all elements of the narrative and not just the sequence. For instance, if there are contradictory indicators on the data level, triangulation of the data sources would be required (Pentland, 1999). Again Pentland (1999) opined that the stories might be self-explanatory, and an explanation is required in understanding the sequence of events.

The application of levels of narrative structure to study

The levels of narrative structure have been modified to be applicable to the research question; this is illustrated in the figure 7 below.

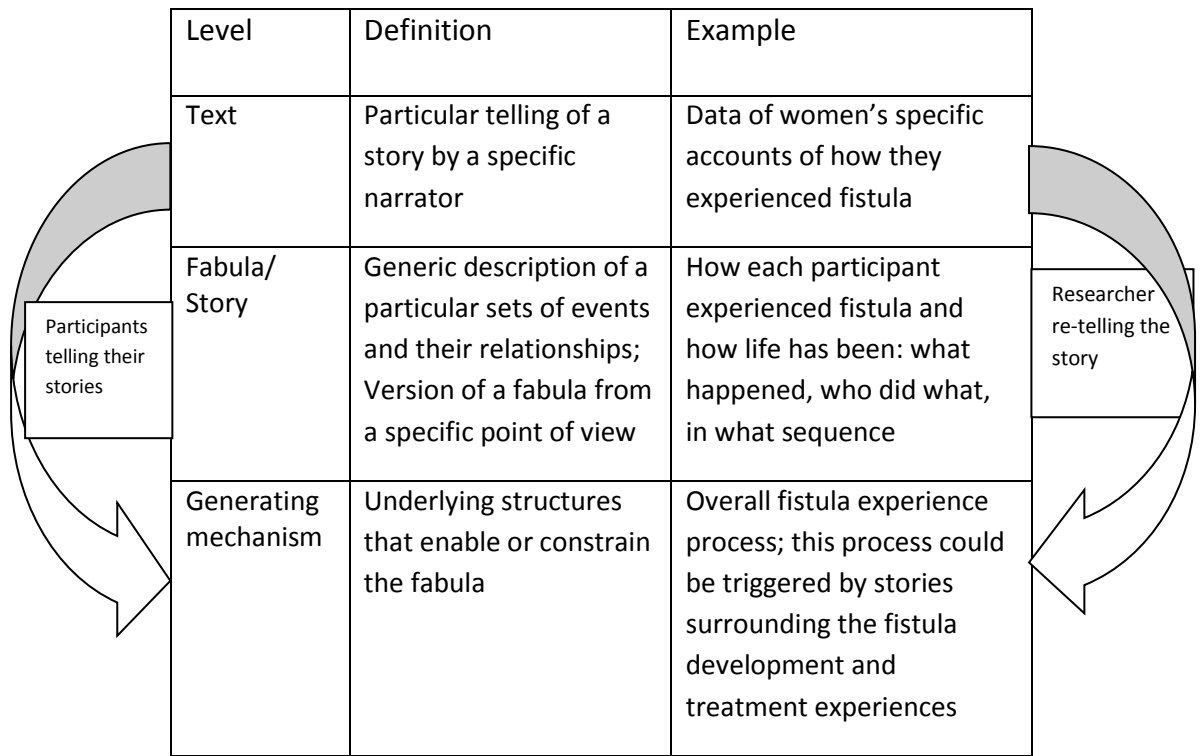


Figure 7: Modified levels of structure in fistula survivors' narrative

Adapted from: Building theory with narrative: from description to explanation (Pentland, 1999).

The generating mechanism level for the study would be outlining the overall fistula experience; the underlining triggers of the events are the stories of fistula development and the treatment (Pentland, 1999). This is the data collection process. As Pentland (1999) pointed out attention should be paid to the specific events not to the explanation surrounding why the events occurred.

The next level is the fabula/ story level; in which participants relate their fistula experiences; detailing out in a sequential order what transpired and those involved in the process/processes. Details would also include the time and specific location/locations (Bal, 1997). The focalization at this point entails the researcher's interpretation of the story being told by the participants; how each participant experienced fistula (Data analysis process of the study).

The text level is the 'content' presented to readers as a series of linked events as experienced by the fistula survivors (Bal, 1997:9). The narrator is the researcher, while the actors are the fistula survivors.

Therefore in presenting the narrative text of women's experiences of living after fistula treatment, the three layered characteristics of text, story, fabula would be utilized (Bal, 1997).

3.2.5 Narratives of Experience

Approaching narrative inquiry as experience - centred, rather than event - centred, helps to capture the three essential components of narrative inquiry. These components are: the talk provides an identity to the narrator's story and not an event; it is a representation of itself and might have numerous meanings; it involves interaction between the participants and the researcher to generate the story collectively (Andrews et al., 2008). Narrative inquiry according to Clandinin (2008) commences in experience that is communicated in lived and recounted stories. Based on the Deweyan theory of experience the narrative inquiry focuses on individuals' experiences, the social, cultural and organizational narratives within which the experiences are located, shaped, communicated and performed (Clandinin and Caine, 2008).

In approaching narratives as experience, Andrew et al (2008) cites personal experiences as being different from other accounts. This is based on the following assumptions; they are sequential and meaningful, meaning could entail expansion of context and materials being studied; it is the human means of making sense; it involves some element of representations and reconstructions over time and places; and finally it entails the transformation of the participants (Andrews et al., 2008). Generally, researchers conducting experience-based narrative usually rely on spoken, written, audio or visual documentation of participants' stories (Andrew et al, 2008).

3.3 Narrative and Illness

Illness experiences can be viewed as an external event that interferes upon life progression (Hyden, 1997). Severe illness leads to what Frank (1995: 1) refers to as a "loss of destination and map" that had provided guidance to the person's life. The illness

confers a new identity in the medical world, “patient” (Frank, 1995: 5). In the modernist period assuming Parson’s “sick role”, according to Frank (1995: 5-6) was a narrative surrender in the “illness experience”. Consequently, personal narratives are expectedly captured in medical terms, with the physician’s becoming the narrator (Frank, 1995). Illnesses however are more than biological reality, they are equally socially fabricated events, represented through speaking, most specifically by narratives a basic method of discourse (Linde, 1993, cited in Greenhalgh and Hurwitz, 2004). For women with fistula, the uncontrollable wetness and the smell becomes their identity, which leads to physical and moral offence to their husbands, families, friends and neighbours (Wall, 1998). Modern medicine however lacks the metric for existential attributes like despair, hope and grief which usually are part of illness experiences (Kleinman, 1988). These typically have been reported about women with fistula, as the psychological consequences of living with the condition.

Postmodern times have led to the return of the voice to personal narrative (Frank, 1995). Consequently, postmodern illness experience is a musing on “body, self, and the destination that life’s map” directs (Frank, 1995:7). According to Greenhalgh and Hurwitz (2004: 6) illness narrative offers “meaning, context and perspective to patient’s” dilemma; providing an understanding that no other means would have given. Patients’ narratives can bequeath a voice to suffering that is beyond the realm of biomedical voice (Hyden, 1997). Narratives of illness are needed for it helps persons that are ill to construct new maps and new opinion of their relationship to the world (Frank, 1995). For instance, through narratives, individual experiences can become a collective phenomenon for social change (Hyden, 1997). The ill person is the “living testimony” of the illness stories; for they are witnesses of the illness they testify (Frank, 1995: 140). Narrative plays a crucial role where there has been a breach between the perfect and the factual, in other words a crisis point (Skultans, 2004). Portraying the illness as a plot therefore gives it a moral meaning embedded within a life story that serves as a symbol for a society of anguish (Skultans, 2004).

In telling stories, this may trigger an emotional reaction in some participants that may border on ethical issues, hence plans need to be in place to address this (Wang and Geale, 2015). Hence, ethical requirements requiring emotional outbursts, privacy and

confidentiality would be adhered to in the data collection process and publication of findings. However, storytelling can equally be a healing process, that can calm the “body and spirit” providing “hope and courage” for exploration and growth (Wang and Geale, 2015: 198). Hyden (1997) opined that illness narrative can be medium of understanding and relating to the illness. Frank (1995) asserted that illness narratives of survivors provided the opportunity to teach others; for in the telling, they also provide healing.

3.3.1 Use of Narrative in Health and Illness

The use of narrative in the field of health according to Hyden (1997) has changed in three main ways over the past decades; thematically, theoretically and methodologically. Thematically – narrative interest is now more focused on patients’ experience and less on clinical practice and doctors’ experiences. Theoretically- it now plays a more central role in reflecting illness experiences within a social context, rather than as a part of clinical practice of detailing observations. Methodologically- there is now more awareness that narratives are constructed based on contexts rather than earlier views that believed identity were conceived on single individual life history (Hyden, 1997).

According to Greenhalgh and Hurwitz (2004), narrative in health provides a framework for a holistic approach to patients’ problems, exposing possible diagnostic and therapeutic alternatives, which have been ignored to the patient’s peril. In research, narratives set a patient focussed agenda, confront received knowledge and produce new theories (Greenhalgh and Hurwitz, 2004). Accordingly, Frank (1995) advocates for a clinical ethic and care that is multi-vocal, where non-medical voices can be heard. The telling of personal illness stories is giving a voice to the body transformed by illness (Frank, 1995). Greenhalgh and Hurwitz (2004) argues further that genuine evidenced based practice, takes for granted interpretive paradigm where patient’s illness experiences and physician-patient encounter is endorsed.

Over the years there has been a “narrative turn” beginning in the social sciences, the shift away from discipline specific and researcher-controlled studies (Riessman, 2008: 14). Consequently, the development of narratives in health as a field of study is a mediation between objective and subjective perspectives and between personal, formal, and social aspects of health and illnesses (Hurwitz, et al, 2004, Riessman, 2008).

Research on illness narratives makes possible the study of illness experiences as a socio-cultural construct; also, as a change and illustration of bodily suffering; finally, it is as an opportunity for the ill to construct their world, identify their purpose and life context (Hyden, 1997).

3.3.2 Narratives in Health Research (Examples of Studies)

Narrative is gradually gaining increasing popularity in health researches. Hyden (1997) in the article "illness and narrative" described different studies that used narrative method in providing an understanding to illness narratives; one of the studies discussed was on HIV illness experiences by Carricaburu and Pierret (1995), it focused on how HIV positive men in France reconstructed their identities. Hurwitz et al (2004) edited a chronicle of narrative health researches on various aspect of health care in their book "Narrative Research in Health and Illness". This book was a follow up on their earlier book "Narrative Based Medicine" taking note of the new developments and the gaining popularity from multi disciplines within the health profession in the use of narrative inquiry for research (Hurwitz et al., 2004). Riley and Hawe (2005) made a case for the use of narrative inquiry from their study on community intervention program to promote health using narrative. They suggested that narrative inquiry provided a unique insight into the complexities surrounding implementation of community interventions (Riley and Hawe, 2005).

Other examples on studies that used narrative in health issues; Riessman (2008) discussed her study on infertility in South India, how women make a sense of their condition and the actions of their families and community. A study by Orkin and Newberry (2014) titled "Marathon maternity oral History Project"; exploring rural birthing through narrative method is another example of study that used narrative inquiry. The main objective of the study was to understand how rural community understood and valued child delivery and maternal health care. Using purposive sampling, eleven women gave an oral history of their birthing experiences. Orkin and Newberry (2014: 64) could conclude that using the methodology allowed the voices of the women to be heard, which was vital for "clinical decision making" and health system

designs. They argued that this might not have been possible if they had used conventional qualitative or quantitative research methods (Orkin and Newberry, 2014).

3.3.3 Methods of Collecting Data Using Narrative Inquiry

This is by narrative interview or episodic interviews (Flick, 2014). In narrative interview, the participant is asked to recount the story of interest that related to the research question. This is done in a consistent manner with all the significant events recounted from the beginning to the end (Hermanns, 1995, cited in Flick, 2014). The theoretical background of narrative interview is based on analysis of subjective perceptives and activities; wherein the research question seeks to focus on historical processes against the background and in the context of specific situations. Narrative interview is also known as the “life story/ history interview” or the Biographical narrative interview by different authors (Wengraf, 2004, Atkinson, 2007, Bold, 2012b). On the other hand, episodic interview is also a method of collecting narrative data. However, It involves interviewing participants on situations relevant to the research question in which they have had an experience (Nettleton, 1995). Episodic interview is based on numerous theoretical assumptions. One of which is that participant’s experiences of certain events are “stored and remembered” as episodic stories and semantic knowledge (Bauer and Gaskell, 2000, Flick, 2014: 273).

3.4 Narrative Analysis

Narrative analysis refers to a group of methods of interpreting storied form texts (Riessman, 2008). It is a process through which researchers gain an understanding of the intricacies of personal and social interactions (Esin et al., 2014). Narrative analysis is a component of the extensive field of narrative inquiry, which is a method of carrying out a case centred research (Riessman, 2008). The analytical methods are suitable for interpreting numerous varieties of texts, oral, written and visual (Riessman, 2008). The “cases” that is the basis of study can be individuals, groups, communities, organization or nations (Riessman, 2008: 11). The researcher focuses on sequences of action; “particular actors, in particular places, at particular social time” (Abbot, 1992, cited in Riessman, 2008: 11); seeking to gain an understanding into the how and why of a story in addition to the content of what is spoken. The researcher is provided with helpful

tools to understand the diversity and the various levels in stories; instead of treating stories merely as just “coherent, natural and unified entities” (Andrew et al, 2004, cited in Esin et al, 2014: 203).

The analysis of the narrative data is a process that is tailored to suit the research. The researcher can modify or adapt the methods to suit the context of their inquiry (Riessman, 2008, Bold, 2012a) Different models of narrative analysis have been developed. The method utilised for this study was developed by Emden (1997) but influenced by Polkinghorne (1988) and Mishler (1986) narrative analytical procedure; Emden’s method allows a descriptive interpretation of the narratives in a sequential order. The strategy of the method is a 2 path procedure of narrative analysis using core story creation and emplotment (Emden, 1998).

Narratives usually are collection of individual stories. The core story creation is a strategy of shortening a complete story into a shorter version for the narrative analysis procedure (Emden, 1998). Stories are events that occur within a context of time and usually are not related in a chronological order (Emden, 1998). Core story creation involves an eight-step procedure:

1. The full interview text is read several times over within a prolonged period of time (several weeks) to understand its content.
2. All the interviewer questions and comments are deleted from the full interview transcripts.
3. All the words that is unrelated to the main idea of each sentence or set of sentences spoken by the participants are deleted
4. The newly constructed texts are read over for to check if they make any sense.
5. Steps three and four are repeated several times over, until convinced that all main ideas are included, and unnecessary content are removed whilst returning to the full text to cross check as often as required.
6. Portions of constituent themes (subplots) are identified from the concepts within emerging the text.

7. Portions of themes are joined together to create one coherent story, or series of core stories.

8. The core story is returned to the participant for member validation. Participants are asked, 'Does it ring true?' and, 'Do you wish to correct/develop/ delete any part?'(Emden, 1998)

The core story is made up exclusively of the participants words and is about ¼ of the length of the full story(Emden, 1998)

The next stage is the emplotment. The plot can be referred to as the theme or main point of the story(Emden, 1998). This is the process of ascribing sense to the story; It involves identifying of one or more plots in a story, to reveal the significance of the story (Emden, 1998). A plot can knit together a complex of events to create a single story. It takes into account the historical and social context in which the events occurred and equally it recognises the significance of unique and peculiar occurrence (Emden, 1998). Emplotment is a 'dialectic process that takes place between the events themselves and a theme' which reveals their significance and allows them to be knitted together as parts of one story (Polkinghorne, 1988: 19-20).The process commenced with the identification of subplots within the stories and a probing back and forth for what was significant about these subplots, or what was distinctive about them, and then additional probing back and forth across stories, comparing and contrasting these distinguishing or important features, to see if they were common to more than one story (Emden, 1998). The emplotment process is undertaken both within and across the core stories and the transcripts of the participants

3.5 Ethical Consideration in Narrative Inquiry

Narrative inquiry is a "relational research methodology"; hence ethical considerations are crucial throughout the study (Clandinin and Caine, 2008: 545). This is because in narrative inquiry, the researcher has a dual role; "intimate relationship with the participant" and professional obligatory role to the academic community (Clandinin, 2007). The relational ethics requires a responsibility to maintain self-respect, confidentiality and wellbeing of participants, which sometimes is in variance with the

academic role that demands precision, truthfulness, and interpretation (Clandinin, 2007). The researcher requires clear recognition of this predicament. The ethical consideration is addressed in the following:

1. Ethics of the relationship: this would be based on clearly spelt out implicit and explicit contracts; who the researcher is, purpose of the research, freedom to participate or withdraw at any point, permission to tape record interview (Clandinin, 2007). Implicit contract would be pursued by developing a good rapport and trust; this would be achieved by maintaining a non-judgemental attitude, showing empathy, concern, tolerance, respectfulness and emotional competence in handling emotional situations (Clandinin, 2007).
2. Ethics of the report: this would be based on the researcher's interpretation of the text; attention would be paid to total honesty of the researcher's reflexivity, which would clearly describe the biases, goals and positioning of the interpreter, circumstances through which knowledge was produced (Clandinin, 2007). With the researcher taking full responsibility for the report (Clandinin, 2007).
3. Ethics of the design: attention would be paid to cultural values of the participants in the conduct of the interview. As a member of the community, acceptable cultural norms would be adhered to in upholding sound ethical practice.
4. Ethics guidelines and board approval; attention would be given to meeting the ethical requirements of the Ethics committee of the Faculty of Health Sciences. Ethical approval would also be sought and obtained from the Health Research Ethics Committee of the Bingham University Teaching Hospital, Jos, Nigeria. These ethical guidelines would guide the conduct of the study. This will include seeking the informed consent of each of the participants.

3.6 The Approach for the Study

From the foregoing examples on studies that employed narrative inquiry particularly the Orkin and Newberry (2014) marathon maternity studies, it is apparent that narrative inquiry would be an appropriate research methodology for this study. Furthermore, the sequential order of the fistula ordeal makes the story telling approach of narrative

inquiry an applicable method. As demonstrated in the literature review, it is an experience laden ordeal presented as a series of sequential events with other social factors that led to the development of fistula (Wall, 2006). The episodic interview has been considered appropriate to generate the data required. Episodic interview can provide the opportunity to recount concrete account of the women's specific experience with regards to the research question. Furthermore, episodic interview can generate everyday knowledge (Flick, 2014). This is crucial in understanding the details surrounding the fistula experience, particularly with the interaction with the other social actors. Again, the interviewing procedure allows for exploring definite situational context in which small changes take place and the general cumulative effect of such changes (Flick, 2000).

3.7 Conclusion to Chapter

This chapter discussed the methodological choice for the study. It began by justifying the choice of a qualitative research and expounding the philosophical paradigm that guided the study design. Discussions also centred on how quality and ethical principles are upheld in qualitative research. The focus of the discussion then shifted to the choice of methodological approach, highlighting what narrative inquiry is and justifying the choice. The discussion also considered issues surrounding narrative inquiry and how to address them. Additionally, the narrative theoretical framework was explained, as well as discussions on narrative in health research, methods of collecting data and analysis and narrative inquiry ethical issues. The concluding part of the chapter summarized the narrative approach adopted for the study. The next chapter provides details of the method of carrying out the study.

CHAPTER FOUR

METHODS

4.0 Introduction to Chapter

This chapter presents the research question and objectives and how the study was conducted. This includes a description of the study sites and how the study participants were sampled. It also provides the description of how data was collected and how rigour was maintained during data collection and analysis. Additionally, it incorporates the method of analysing data and how the ethical procedure for the study was enacted.

4.1 Research Question

How do women attending a reintegration service describe their experience of living with fistula?

The **specific objectives** were to explore the following:

1. The childbirth experiences that led to fistula formation
2. The experiences of women while living with fistula
3. The role of family and community while living with fistula and after treatment
4. Women's health seeking behaviour and coping strategies after developing fistula
5. The experiences of women after fistula repair
6. What are their experiences of rehabilitative services

4.2 Research Design

4.2.1 Study Site

The study centre was Evangel Vesico Vaginal Fistula Centre(EVVF) of Bingham University Teaching Hospital (BHUTH) Jos, in North Central Nigeria, established in 1992 (Kirschner et al., 2010). The choice was based on the fact that it is centrally located in the North of Nigeria where the prevalence of obstetric fistula is highest (0.5% north as against 0.3%

in the south (FMoH, 2013). Also, BHUTH is my work place and I have carried out various researches within the fistula centre on other areas of interest.

The centre has 110 beds with 20 for immediate surgical care, 10 for on-going surgical care and an 80-bed hostel for patients awaiting surgery, in rehabilitation and long-term care. The centre has one master surgeon and two others who perform moderately difficult cases. Annually it carries out over 350 repairs in the centre and another 100 during outreach to other states in Nigeria. During the outreach, complex cases are referred to the centre for treatment. Over 10,000 surgeries have been carried out in the centre since 1992. Over the years the EVVF centre has become known for handling complicated and irreparable cases (Kirschner et al., 2010). As such, in addition to its central location it attracts a large volume of care seekers from various parts of the country (Daru et al., 2011). A good mix of clients who have undergone treatment were therefore viewed as possible participants; hence the centre became a good choice as the study site.

The services of the EVVF centre are funded by donations from international organisations, charities, national, local organisations and individuals. The centre provides training for surgeons, nurses, midwives and community health workers in Adamawa, Plateau, Nassarawa and Kaduna States (EUVFC, 2017). Onsite training organised by the centre on the use of partograph to monitor child delivery by health workers has become an on-going project. The EVVF centre also commenced rehabilitation work with women in 2002. Since then over two hundred women have acquired sewing and knitting skills to enable them to become economically empowered in their communities (EUVFC, 2017). Through donor contributions, some women have also been the beneficiaries of sewing machines along with micro credit loans to enable them to commence small scale businesses so they can achieve economic independence (EUVFC, 2017).

4.2.2 Sampling

Sampling Method

Following ethical approval, the participants were identified through hospital records; names that had phone contact numbers were taken of 20 women that met the inclusion criteria, through the records of the rehabilitation program coordinator. The initial contacts were made via phone, but as most of the numbers called were unobtainable another strategy was employed in terms of direct contact with the women. Six women were contacted, three lived locally and the others lived outside of the city, these women agreed to travel down during the EVVF reunion program. Information leaflets were circulated and through physical contacts during the EVVF reunion program, five women were recruited. Additionally, nine other women were recruited through snowballing from the first contacts.

The purposive method of sampling was used, to identify women that fitted the inclusion criteria and thus able to answer the research question. In qualitative research purposive sampling is mostly used to identify and select information laden cases related to the phenomenon of interest (Creswell, 2007, Palinkas et al., 2015). Hence women who had undergone fistula repair and who had participated in the rehabilitation program provided the basis of the study sample from the study centre. Additionally, due to the difficulty of locating participants through phone contacts, snowballing was equally employed, and this provided most of the participants.

Sample Size

The pre-determined sample size was 15-20 women. In narrative research sample sizes can be one or two individuals, but to generate a collective story a larger pool of participants can be used (Creswell, 2007). Twenty women were contacted with 15 women being aged between 21- 52 years who met the inclusion criteria. The inclusion criteria included:

1. Women treated for obstetric fistula
2. Treatment undertaken in the last one year or more

3. Have undergone the reintegration/rehabilitation program of the fistula centre
4. Have returned to their community or community of their choice

The exclusion criteria were:

1. Women with significant mental health issues
2. Women that were victims of rape

Those excluded were:

Non-obstetric cases, for example, two women had congenital fistula, and three women were still undergoing rehabilitation program.

4.3 Ethical Issues

Ethical approval was obtained from the ethics committee of the Faculty of Health Sciences, University of Hull and from the Health and Research Committee (HREC) of BHUTH, Jos- Nigeria (See appendix 2, p.331). Participants were taken through the ethical process of information on their rights, by reading through the information sheet in their native language. The information provided included the purpose of the study, why they had been selected, deciding to participate or not, what will happen if they decide to, what will be discussed, the possible risks and disadvantages and benefits, the role of their spouse/ supporter if necessary, confidentiality and what will happen with the results (see appendix 3- information sheet, p.333). The following was undertaken to maintain the ethical codes:

Autonomy- the information was provided in the local language, so participants were fully informed. The women were provided time to decide whether they would participate and were equally assured that participation was voluntary and could withdraw at any point in time during the course of the process. Only those willing to participate were enrolled for the study. Two women displayed emotion while narrating their stories; one interview was discontinued, and the woman was provided with psychological support by the trained counsellor in the centre. The interview was held one week later when she was happy to go on. On the other hand, the second woman

was happy to continue with the interview after receiving some counselling by the trained counsellor.

Beneficence and non-maleficence-- women were informed of the potential benefits and risks of participating in the study (appendix 3 on information sheet, p.333). Women were equally assured of the confidentiality of the study and permission was obtained for disclosure through publications and presentations. In the pursuit of non-maleficence, strict compliance to confidentiality and data protection was maintained throughout the period of study. Data was kept in a secured specially created folder in my personal laptop with a secured password. Hard copies were kept in files in lockable cabinets. Pseudonyms were given to each participant to protect the identity of the participants. Equally, pseudonyms were used in identifying the voice of the participant in quotes used in the write up.

Justice- In maintaining justice, every effort was taken not to exploit the women by considering their feelings while conducting the interviews (as discussed above). Recognition has also been given to the vulnerability of participants in the write up, and the fact that the findings of the study could make a significant contribution to the provision of care and practices in maternal health service delivery. The findings of the study will be disseminated through publications, conferences, and a submission to the HREC of BHUTH, Jos and the National Fistula Working Committee of Nigeria. Avoiding over exploitation and abuse of participants in qualitative research is an important consideration which recognises participants' vulnerability when contributing to research and ensures everyone is treated equally and with fairness (Orb et al., 2001).

A letter of consent, written in the Hausa language, was read out to each woman and they were reassured of the confidentiality of the process. All the women who consented and signed or thumb printed the form were enrolled. No woman withdrew from the study.

4.3.1 Ethical Consideration in Narrative Inquiry

In addition to the above, since narrative inquiry is a "relational research methodology" (Clandinin and Caine, 2008: 545); so further attention was given to ethical

considerations that are unique to narrative inquiry (as highlighted in the methodology chapter). These additional ethical considerations were addressed as follows:

1. Ethics of the relationship: the role of the researcher was clearly spelt out. In developing a good rapport and trust; efforts was made to maintain a non-judgemental attitude, showing empathy, concern, tolerance, respectfulness and emotional competence in while dealing with the emotional outburst (Clandinin, 2007). Counselling was provided when there was an emotional breakdown as stipulated in the plan of action.
2. Ethics of the report: honesty is required in acknowledging the impact of the researcher's views on interpretations (Clandinin, 2007). Therefore, the information in the introduction of the study on the rationale of study describes the biases, goals and positioning of the interpreter, as this invariably will impact upon how knowledge is produced. Furthermore more information on the role of reflexivity in the interpretation has been provided in the conclusion chapter (Clandinin, 2007).
3. Ethics of the design: attention was given to respect cultural and religious values of the participants while conducting the interview. As a member of the community, acceptable cultural norms were followed in upholding sound ethical practice. For instances, the Muslim women's interviews were conducted by women only research team, in respect of women's privacy on feminine matters based on Islamic teachings.

4.4 Data Collection

This is the 'fabula' level of the story generation (Pentland, 1999). An episodic narrative interviewing method was used to generate data. The interview commenced by asking participants to tell the story of their experience with living with fistula. An interview guide (see appendix 5, p. 338) was used to provide prompts to guide the discussion on specific episodes that participants might not have mentioned that was related to the research objectives. The demographic data of each participant described their current characteristics prior to each interview. The interviews were conducted in the local Hausa

language assisted by a trained research assistant who was well versed in the local language. After each interview audio recording were transcribed and translated by a native speaker. This was then compared with the field notes; and served as the raw data by the researcher. Additionally, each translated transcript was reviewed by listening repeatedly to the recordings by the researcher. Back translation of sample transcripts was carried out by another native speaker (details of how accuracy was maintained are provided in section 4.6 below). Follow up face-to-face interviews and follow up telephone calls were made to clarify issues after listening and reading the transcripts. Data saturation was achieved by the time the 15th participant was being interviewed as no new information was emerging. The story of the last participant appeared to confirm the main elements of all the previous stories collected (Creswell, 2007).

Table 4.1: Summary of participants' interview process

Name‡	Number of interviews	Duration
1. Margaret	3	3hrs
2. Rose	4	2hrs
3. Damaris	3	1hr 30mins
4. Christy	2	1hr 10mins
5. Alheri	3	2hrs 20mins
6. Patience	2	1hr 10mins
7. Asmau	2	1hr 15mins
8. Sarah	2	1hr 35mins
9. Halima	4	4hrs
10. Talatu	2	1hr 25mins
11. Nanchit	2	1hr 30mins
12. Loveth	2	3hrs 30mins
13. Gladys	2	1hr 30mins
14. Fatima	3	1hr 30mins
15. Maimuna	2	1hr 30mins

Follow up interviews for member validation was conducted at the study site from 8th - 10th March 2017. The core story transcripts for the 3 case studies participants were read through with them. Halima and Margaret, offered more information, while Loveth confirmed the content as true representation of her story. Interviews were held with six participants to clarify grey areas.

4.5 Data Analysis

This is the focalisation level of generating the narratives (Pentland, 1999). Data were analysed using narrative analysis following the 2-path procedure of core story creation, and emplotment by Emden (1997).

A. Core story creation involved following these steps:

1. The full interview scripts several times were read through over a period of time that took several weeks in order to grasp the full content, audio recordings were also listened to over and over again during this period
2. Next all interviewer questions and the comments from the full interview scripts were deleted
3. All words that detracted from the main idea of each sentence or group of sentences spoken by the participants were deleted.
4. The script was read through to check that it made sense.
5. Steps three and four were repeated several times, until satisfied that all key ideas are retained, and extraneous content were eliminated. While doing this it was necessary to return to the full script as often as necessary to recheck that this was achieved.
6. Sections of constituent themes (subplots) were identified from the ideas within the script.
7. Sections of themes were moved together to create one coherent core story.
8. The core stories were returned to the three participants that were selected as case studies, to ask, 'Does this look like what you told me?' and, 'is there anything you are not comfortable with or you want to add or want removed?'

See appendices (1a, 1b and 1c) for three core stories.

B. Emplotment procedure (table 4.2 sample of the emplotment process)

Table 4.2: Excerpts of core story and emplotment process

Core story excerpts	Events	Subplots	Plots
<p>Halima's story</p> <p>I am from Minjibir Local Government, Kano State. I was given out in marriage at the age of 14..., after I got married I got pregnant when I was 15 years... I was in labour for 3 days. I used to see a doctor before then and the doctor told me that the child was too big and that I need to be taken to the hospital when it is time for me to deliver. But because we have our culture like that of the Fulanis, my parents came and took me from the town (Lagos) where we were staying with my husband to the village that it is not good for me to deliver alone because I was alone with my husband at that time. So, I was taken to the village.</p> <p>I still remember what they told me at the Antenatal Clinic that when it is time to deliver I should go to the hospital. I didn't tell them that until I went into labour, that was when I told them that the doctor had told me that the child is too big so when I start labour I should go back home so that I will be taken to the hospital, that I should not agree to anyone making me give birth at home. My late grandmother said, "look at you!!...there are smaller girls than you who have given birth at home and you are hoping that you will be</p>	<p>Early marriage</p> <p>Prolonged labour</p> <p>Awareness of doctor's warning at ANC for SBA</p> <p>Cultural influence place of delivery- transfer to village by parents</p> <p>Influence of grandmother on home birth & delay to seek care</p> <p>Prolonged labour</p>	<p><i>Fistula formation</i></p> <p>Influence of others</p> <p>Influence of others</p>	<p>FISTULA ORDEAL</p>

<p>taken to the hospital!" I told her that it was what the doctor said, and she said I should shut up. I started labour on Tuesday; I did not give birth and went through Wednesday. My mother was not home when I started labour on Tuesday, she had gone for a wedding. She returned on Wednesday, she was the one that insisted that I needed to be taken to the hospital that Wednesday. But our village is off the road, there is only one vehicle in the village. They went to get the vehicle but were told that he (driver) has gone out with passengers that we should wait for him to return. He did not come back until around 9:30 PM. That is when they took me to the clinic but the clinic in our village was very small. From there, they told us that I cannot give birth there, that I should be taken to a bigger hospital in Kano city. I was taken there on Thursday and I spent the night there up until the early hours of Friday. Initially, they said they were going to operate but because we don't have money at hand and they said they will not touch me until I pay, the surgery was not done. One of the doctors said since they are not going to operate, they should at least try to remove the baby because the baby as of that time was already dead. So one woman climb on top of me and was pushing and squeezing while the doctor had his hand in my private part and the two of them were struggling to remove the baby. At last they succeeded (...) We went back home... I was lying down, when I made an attempt to sit up, I heard something pouring out.</p>	<p>Mother influence decision to seek health care</p> <p>Remoteness location- lack of transport, further delay</p> <p>Transfer to another hospital- lack of facility for EmOC, rural location</p> <p>Delay – lack of finances to pay for C-section</p> <p>Medical malpractice- traumatic bodily experience</p>	<p>Geographical location and transport</p> <p>Poor healthcare system</p> <p>Poor healthcare system</p>	
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<p>My beddings will get wet and my mother will change them. We kept wondering what was happening</p>	<p>Body awareness- urine leak Perplexed</p>		
<p>Loveth's story</p> <p>I am from Gure, in Kaduna State...I gave birth three times; it was at my fourth that I had that problem. I attended ante natal care, but there was no problem through the pregnancy. I started feeling pains in my stomach, so I went to the hospital that same day... I actually walked with my two legs to the hospital... When I entered the hospital, they said, "See, the child is coming out." The child started coming out head first, that was around 4 p.m. When the head came out, it stopped there, it neither came out no went back in. There is no doctor in that hospital. The whole nurses spent that night on me, later, I felt as if my body no longer belongs to me. I will come down from the bed and they will pick me up and put me back. The next morning, they pressed my stomach like this (demonstrated how) and I started bleeding. They asked us to go into the hospital in town after this...Our road was bad then, so they put me on a motorcycle. If we reach where the road is very bad, they will lift me up...my husband and my father will lift up like this (demonstrated how) until the rider passes the very rough spot that was how we were able to</p>	<p>Fourth delivery ANC attendance Early presentation for skilled birth care Obstructed labour- no doctor to perform EmOC Delay for referral by SBAs Referral after manipulation that caused bleeding</p>	<p><i>Fistula formation</i></p> <p>Poor healthcare system</p> <p>Geographical location and transport</p>	<p>FISTULA ORDEAL</p>

<p>reach the side of road that leads to Saminaka. By the time we reached Saminaka, my vagina was already swollen so they say there is no way I can deliver on my own, they will have to operate, and we will have to put money down before the surgery. My husband had no money, my mother had no money. ..They insisted they must provide the money...My mother spent the whole day in Saminaka looking for money among relatives but couldn't get anything. There I was....no food or water could enter my mouth. She came back and begged the doctor. Finally, they agreed, checked that there was fuel in the generator and the surgery was done around 12 midnight the next day. They removed the dead child and I was in a very bad shape...and leaking urine.</p>	<p>Remote location- bad road, no vehicular transport</p> <p>Further delay- lack of finances to pay for C-Section</p> <p>Negotiate for care- further delay</p> <p>Outcome of C-section, stillbirth, leak commenced</p>	<p>Poor healthcare system</p>	
<p>Margaret's story</p> <p>I started leaking urine as a result of delivery. I was 18 years of age. I am from Kargarko village in Kaduna state. I started labour in the night and was on till the next day. My mother in law was there, there was no plan to go to the hospital because of money issue. I did not even register (Ante natal care) until the last month because they said they did not have money (...) as I was labouring till the next day...when it was not possible, my husband's uncle that came from the town advised them that I should be taken to the hospital. I was</p>	<p>Cause of VVF</p> <p>Home birthing experience- prolonged labour</p> <p>Influence of mother in law- birth attendant</p>	<p><i>Fistula formation</i></p> <p>Influence of others</p> <p>Poor healthcare system- user fee barrier</p>	<p>FISTULA ORDEAL</p>

taken to the clinic where I did my ante natal, they said they were not able, so send me to another hospital; it was a private clinic in the village (Kargarko). I gave birth.... I don't know what happened, but as I was sitting down after delivery, I notice something just dripping from me and I wasn't feeling like urinating. We were in this hospital for one week and I couldn't walk. They put catheter into me. The nurse there after some days removed the catheter and I was dripping urine (...)

Influence of finances –
 decision of home birth
 Decision to seek care-
 influence of relative from
 city
 Delay at health facility-
 lack of capacity provide
 care
 Transfer to another
 facility
 Commencement of leak
 after

Geographical
 location- rural
 city
 Poor healthcare
 system

The process of emplotment commenced with the identification of subplots within the core stories. And then a probing back and forth for what was significant about these subplots, or what was distinctive about them, and then additional probing back and forth across stories, comparing and contrasting these distinguishing or important features, to see if they were common to more than one story.

The searching resulted in the recognition of three main sets of events that were common to all stories, and the construction of three plots that recognized the importance and the function of the 'individual events', and a joining together [of these] as a single story (Emden, 1998). The 'events' are the elements of the stories that signified the participants' lives as related by them, in the form of 'people, places, happenings, thoughts, and feelings'- the 'grasping together' is the sense making of the whole events as one story by the narrative researcher (Emden, 1998: 37).

4.6 Maintaining Rigour during Data Collection and Analysis:

Credibility

- Development of a Research Relationship

The annual reunion of EVVF centre coincided with the data collection hence it provided a unique opportunity to develop a research relationship with all the participants. Visits were paid to the rehab village to sit, join in activities and chat with women who had come in for the reunion program. And, I participated in the funfair activities that were taking place during the program. As the days went by, I was now being referred to as "auntie/mummy mai tambaya" (mai tambaya means the interviewer). To be called an endearing name of auntie/mummy; was a sign of respect, trust and rapport development. As a result of this contact, follow up interviews to clarify grey areas was made easier and it was observed women were more willing to provide information. Participants were eager to share their stories saying, "Let my story be heard, perhaps my life will improve as knowledge will increase on how to help my situation".

- Peer Review
1. Supervisors were the major peer reviewers; Skype meetings were held fortnightly. Transcripts were reviewed after the first three interviews; and there was need to review the interview guide to generate deep responses. Follow-up interviews were thereafter conducted for the first three interviewees
 2. The Fistula Director Centre: Research was taken as project for the centre as findings will be used to restructure the rehab program. Meetings were held each week to discuss the progress of the data collection. And before departure from the field a debriefing meeting was held with the Director. Furthermore, there has been on-going correspondence on phone/Skype and email.
 3. Member Validation: Clarifications were sought through interviews or phone calls to clarify any grey area. For instance, after going through transcripts I cross checked evolving interpretations from participants e.g. you mentioned you were told to come back after 3 weeks to see the doctor, this was during the raining season, but you waited till January, why and what happened?
Follow up face to face interviews were conducted (March 8th -10th 2017) at the study centre for the three case study participants and six of the other participants after data analysis had commenced. The case study women were taken through the core story created to verify any discrepancies with their accounts, what they wanted to be changed or included. The women were happy with their accounts. Case study one and two provided more information.
 4. Rehabilitation Centre Records: To validate accounts on skills program and date of discharge.
 5. Informal discussions were held with chaplains in charge of rehab. This was to verify information on rehabilitation services provided by participants and the methods of enrolment.
 6. Observation: I visited the rehabilitation centre to observe activities. This was to confirm the services provided and validate the narratives of participants. Informal talks were held with current rehab trainees and the trainers.
 7. Debriefing Session: Presentation of preliminary results was done on the 8th March 2017 at the study centre to members of staff; in attendance were the chief Surgeon (Director), Nurses, Chaplains, Data Entry Clerks and Theatre staff.

Dependability

Efforts were taken in maintaining methodical accuracy in documenting and transcribing data details. Transcription and translation was undertaken by a native speaker with experience in health research, in response to addressing the dilemma of working with translated data in narrative inquiry highlighted in section 3.2.1. Other efforts were, frequent cross checking of data and interpretations was undertaken; this involved listening and re-listening to tapes and transcript to check out any left-out information, pauses, change of tone (recapture mood as presented during the interview). Phrases used in the local language were verified with different native speakers to ensure the right interpretations were given. Furthermore, translated transcripts were back translated to ensure the interpretation was accurate.

Transferability

To enable some generalizability of the findings of the study, efforts have been taken to provide a detailed contextual background to the study. The rich description of the study setting; Nigeria's history, economy and health development, maternal health issues, and the contextual issues surrounding obstetric fistula formation should guide potential use of the findings. Furthermore, the demographic details of the participants have been provided to allow informed judgement on how findings can be applied (Marshall and Rossman, 2011).

Confirmability

In ascertaining the confirmability of the research process, efforts were made to create a detailed audit trail of how the research choices were made in the methodology chapter. Also, made explicit were the reasons for the choices made in the research process. In addition to these, as qualitative research the participants' views were taken as the sole representation; quotes were provided as evidence as well as description of events were narrated majorly using the participants' voices. Furthermore, the techniques used above to determine credibility, dependability and transferability together further constitute the core for ascertaining confirmability of this study (Lincoln and Guba, 1985).

4.3 Conclusion to Chapter

The chapter presented the method of carrying out the study. It provided a description of the study centre, how sampling was carried out, how data were collected and analysed. A sample of the process of employment was provided. It also provided details of the ethical procedure that was carried out for the data collection and steps taken to ensure the trustworthiness of the data. The next chapter presents the findings of the study.

CHAPTER FIVE

FINDINGS

5.0 Introduction to Chapter

This chapter provides the results of the data collected. As earlier identified in the methodology chapter, this is the 'text' level, where the series of events as narrated by the focal actor (fistula survivors) is presented (Bal, 1997, Pentland, 1999). Data is presented with the "narrative voice and the evaluative context" to reflect a narrative form (Pentland, 1999: 720); The results are presented in the form of descriptions of particular sets of events and their relationships based on the point of view of the participants.

The chapter is divided into three sections. The first section, presents the demographic information table, and provides a summary of the relevant historical and social background of participants. The second section is the case study presentation, wherein one participant's core story is provided as an abstract; the full story, with two others are presented in the appendix (appendices 1a, 1b and 1c, p. 297). These case studies are paradigm examples of the typical narratives of participants; the core story helps to portray a complete story; how it was told, with the life meanings participants gave to their experiences (Hyden, 1997, Emden, 1998). The third section is presented as 'emplotments' (Emden, 1998), these key plots are the thematic sequential presentation of the stories identified from the core stories of the women's narratives (Emden, 1998, Mattingly, 1994). The plots are the descriptive summary of all the narratives. This section explores the significances of the stories (Emden, 1998). Sections two and three, present the findings as a 'synthesis through narrative' (Bleakley, 2005: 537).

5.1 Demographic Information

Background information on the participants are provided in table 5.1 below; it provides a historical summary of the socio-economic status of the women prior to development of fistula. The demographic information is the 'indicator of context' as earlier identified

in the methodology (Pentland, 1999), and forms part of the evaluative process in the discussion of finding

Table 5 1: Demographic information of participants

Name#	Current age	Age at fistula development (yrs)	Employment Status (pre-fistula)	Educational status (pre-fistula)	Number of living children (pre-fistula)	Marital status (with fistula)	Delivery fistula occurred	Outcome of delivery	Current marital status (after repair)	If married Number of wives (after repair)	Marital position	Current employment status	Number of children after repair	Location of incidence	Current home
1. Margaret	21	18	Student	Primary	Nil	Separated	First	Stillbirth	Single	NA	NA	Student/hospital cleaner	Nil	Kargarko-rural	Jos-urban
2. Rose	38	15	Unemployed	None	Nil	Divorced	First	Stillbirth	Divorced	NA	NA	Unemployed	Nil	Jigawa-rural	Jos-urban
3. Damaris	33	23	Farmer	Secondary	Nil	Divorced	First	Stillbirth	Divorce	NA	NA	Farmer	Nil	Kalan-rural	Silon-rural
4. Christy	28	20	unemployed	Primary	Nil	Single	First	Stillbirth	Single	Na	NA	Waitress	NIL	Langtang-rural	Jos-urban
5. Alheri	32	20	Farming	Primary	Nil	Divorced	First	Stillbirth	Remarried; separated	3	3 rd	Farming	Nil	Akungwa -rural	Haleyi-rural
6. Patience	37	26	Unemployed	Secondary	1	Married	Second	Stillbirth	Married	1	NA	Knitting & retailing	2	Zing- rural	Zing-rural
7. Asmau	52	42*	Farming	Primary	4	Separated	Fifth	Living	Separated	NA	NA	Farming &retailing business	Nil	Karshi-rural	Karshi-rural
8. Sarah	40	32	Farming	Primary	1	Married	Second	Stillbirth	Married	2	1 st	Farming	Nil	Chuwi sama-rural	Skil-rural
9. Halima	37	15	Unemployed	None	Nil	Married	First	Stillbirth	Married	2	1 st	Trainer& retailing business	Nil	Minjibir-rural	Kano-urban
10. Talatu	33	24	Farming	Primary	3	Separated	Fourth	Stillbirth	Separated	NA	NA	Farming/Tailoring	Nil	Bilin- rural	Bassa-rural
11. Nanchit	40	25*	Farming	None	Nil	Married	First	Stillbirth	Married	1	NA	Farming & brewing business	2	Langtang-rural	Langtang-rural
12. Loveth	38	20	Farming	Primary	1	Widow	Second	Stillbirth	Remarried			Farming/Retailing business	Nil	Kauru-rural	Kauru-rural
13. Gladys	30	19	Unemployed	Secondary	Nil	Single	First	Living	Single	NA	NA	Student	Nil	Giza- rural	Giza-rural

14. Fatima	28	18	Unemployed	Koranic	Nil	Divorced	First	Stillbirth	Remarried	2	1 st	Tailoring & retailing business	Nil	Gashua - rural	Gashua - rural
15.Maimuna	39	25	Unemployed	Secondary	1	Married	second	Stillbirth	Married	2	1 st	Tailoring	1	Dogoruma - rural	Dogoruma - rural

‡ Pseudonyms

* Estimated age

5.2 Core Story

It is important to note here that each woman's story is unique, and none is more important than the other. However, three stories were selected for full presentation as core stories, not as representative but as an illustration of the typical voice of the narratives. The bases of selection of cases are as follows:

- Clear voice of advocacy: a voice for issues women highlighted in the overall data;
- Each story is a representation of different categories/stages of recovery - repaired (dry, mild leak, severe leak).

The summary information on the case studies is outlined in table 5.2 below

Table 5.2: Information on case study participants

Case	Background	Advocacy message
Halima‡	Age 37 years, has had 7 repairs, lived with severe urine incontinence for 22years, still married Current continence status- severe leak	<ul style="list-style-type: none"> • Institutional delivery for pregnant women. • Parents to listen to doctors' advice and discontinue cultural practices on home delivery
Loveth‡	Age 38 years, 2 repairs, 15 years mild leak, remarried Current continence status- mild leak	Women economic empowerment through skill acquisition
Margaret‡	Age 21 years, 1 repair, dry, single Current continence status- dry	Fistula treatment for untreated women with fistula

An abstract of Halima's story is provided below. Her full story and those of Loveth and Margaret are available in the appendix (see page297). Readers are encouraged to read through these stories.

CASE STUDY ONE

Halima‡

5.2.1 Abstract of Halima's story

Halima, a 32-year-old woman is from M, a village in one of the Northern states in Nigeria. Married at the age of 14 years, she thereafter moved to live with her husband in Lagos. Halima became pregnant at the age of 15 years, and during her Ante Natal Care (ANC) visit, due to the baby's size her doctor gave a strict instruction about delivering her baby in a hospital. However, Halima narrated "because we have our culture like that of the Fulanis" that required a woman to deliver at home, her parents, moved her back to the village to have her baby. When labour started, she tried to no avail to tell her grandmother who presided over the delivery about the doctor's instruction. Halima's mother who was not home at the onset of labour on her return finally persuaded the grandmother to take her to the hospital on the second day. But unfortunately, the only vehicle in the village was not available till 9.30pm, when she was moved to the village's clinic. At the clinic, they were referred to the hospital in the city since they could not handle it. The next day she was moved to the city, where there was a further delay due to lack of funds to pay for a C-section. Finally, after another night at the city hospital, a doctor and nurse forcibly evacuated the decomposed baby manually on the fifth day that labour started.

Halima observed her bed getting wet, upon discharge home from hospital, causing her and the mother to be alarmed. Not sure of what was going on, Halima's mother sought counsel from friends who visited; they suggested it was urine leakage and advised going back to the hospital where a diagnosis was given of VVF caused by the prolonged labour. Thereafter, over a five-year period, four unsuccessful repair attempts were made. Upon which she decided to seek cure elsewhere that brought her to EVVF centre in the year

2000. At the centre, Halima was told her case was a complex one requiring diversion procedure of which she declined. Two additional repairs were eventually carried out with no positive improvement. Halima narrated “I was just living like that until much later that I heard about another type of surgery that produces result”, she now returned for her 7th repair attempts in 2015. This repair resulted into a post-surgical complication that Halima believed worsened her leakage. Currently though, Halima alleges the leak has reduced, she maintains she has a severe urine leakage.

Living with urine leakage for the past 22 years has affected Halima’s life. Even though she is still married to her husband, her condition led to his second marriage during one of her hospitalizations. This was a cause of worry since the husband concealed the information from her. Moreover, living with her co-wife has been a challenge, as she faced insults over her condition. Her inability to conceive is also another issue of contention, as Halima related, “She has four children and I don’t have even one...Honestly, this issue is hurting me seriously...” Going further Halima described her concern over her childlessness by reporting “Barrenness is not a small disease to women...” additionally Halima believes her co wife tells people in her community about her condition, thereby contributing to the local gossip of which she describes the ridicule she faces from people waiting to check her back for wetness. Other evidence of stigmatisation as Halima related was “you touch even a plate; you will notice they do not want to touch that plate to use it”.

Halima asserts her husband has never made any financial contribution towards her quest for a cure at the hospital over the years and he wants her to give up and learn to live with her condition, which she finds worrisome and unacceptable. Halima equally alleges her in laws too were not helpful, doubtful of her continued search for a cure, traced her to the hospital to verify her condition. Furthermore, her community members have never assisted her, and she believes their interest in her is just for gossip purpose, to discuss her challenges with urine leakage. Halima undoubtedly prefers her stay in the hospital to returning home, for she feels accepted while in the hospital than at home where she is stigmatised. She therefore prefers her peers as friends and hence no longer finds associating with old friends pleasant and looks forward to her return to the centre for treatment, than returning home. She describes how her peers ‘masu yoyon fitsari’

(the leakers of urine) are available to offer help and support in caring when family is not available to do so.

Halima attended the skills rehabilitation training at EVVF Rehab centre and learnt knitting, during one of her hospitalization in 2003. Since finishing the training, Halima has been involved in training other women in her state (province) and carrying out small business of selling her products. Her rehab has been of great benefit to her because she believes she could never have gotten the skills she currently possesses. Halima asserts that the training has provided her with skills for financial and self-autonomy hence she no longer depends on her husband for daily living sustenance, even though she is still leaking, it has not affected her livelihood. Furthermore, the rehab has provided her with a sense of self-worth to keep going on and living her life despite her persisting challenge of living with fistula.

Initially there were physical difficulties coping with leak, but because it has been a long-standing condition Halima devised methods to handle the leakage. She developed the use of sourcing for soft towels and cutting them into pieces to use as pad to contain the flow. By accumulating many towels and ensuring they are washed and well dried before use, she no longer experiences blisters and rashes associated with rag use. She avoids places where she cannot wash and properly dry her rags, hence she avoids sleepovers and public places. This sometimes makes some of her relations unhappy with her, as she cannot attend all their social functions.

At the peak of her ordeal, she contemplated suicide after a failed surgery, she thought of jumping into a well to end it all. Halima is notably worried over the series of miscarriages and her inability to have a baby since her stillbirth delivery 22 years ago that led to the fistula. Halima related that she experienced sexual difficulties after one of the surgeries, wherein she had to undergo another surgery to allow passage for sexual intercourse. Currently there are no more sexual difficulties except that sexual relation has declined with her husband. Nevertheless, Halima's greatest worry is her childless condition due to the societal expectation of motherhood. She is fearful of losing her husband through divorce or death, believing no one will find her suitable for marriage

because of her condition. Halima believes her life is not a pleasant experience. Halima narrates:

“Honestly, life is not sweet... one has to just bear it. You just have to be patient. I am just ‘managing’ life... Whoever is in this kind of state can only be patient... There is nothing you can do...it is just ‘manage’... yes, it is ‘manage’, what else? I am ‘managing’ life...”

Despite this Halima is still hopeful in God to cure her, which is why she keeps returning to seek cure and not giving up. Halima’s closes her story by offering words of advice. These advices are suggestive that she is very aware of the cause of her fistula. Halima advised parents who were custodians of tradition to abolish customs, which make women deliver at home. She admonishes them on how to avoid the hardship she is facing as a result of such practices, encouraging them to listen to doctor’s advices for institutional delivery. Halima also provided a word of advice to the general public, pleading for women to be allowed to seek prompt medical attention as soon as labour commences.

PS. At the member validation session, Halima confirmed the narratives as presented in her core story. She however added, that she had undergone 14 repairs and not 7 as she earlier reported, 7 she said was the ‘official figure’. Halima asked me to count for myself, as she reeled off the years and doctors that carried out the repairs. Halima related

... “If I tell people 14, how will they look at me, wouldn’t they think there is ‘something’ wrong with me...? What do you want me to say...? I have to say that, so people don’t look at me anyhow...what can I do?” ... just so, I say 7...I tell them 7, yes that one is even bad enough... 7 but it is better than saying 14...”

5.3 Emplotment – Thematic Presentation of Findings

The narratives of fistula survivors are illness narratives. The common threads in the narratives are presented as a beginning plot, a middle plot and an ending plot format in line with the narrative methodological approach (Steinmetz, 1992, Hyden, 1997, Pentland, 1999). These plots seek to merge together intricate events of all the

participants to form a coherent single story (Emden, 1998). The plot lines that structure the illness narrative are drawn from cultural and personal models that are arranged to communicate the experiences in a meaningful and effective way (Kleinman, 1988). The three main plots identified are; 'fistula ordeal', 'treatment process' and 'returning to life' to fit into the sequential pattern. The 'fistula ordeal' marks the beginning of the story, the 'treatment process' the middle, while the 'returning to life' marks the end of the plot of the narratives for the purpose of this research. Nevertheless, as would be seen there is a back and forth shift between the middle and end plots. The cause and effect relationship in narratives resonates in the sequential events that describe the experiences of women (Steinmetz, 1992, Clandinin and Connelly, 2000, Clandinin and Caine, 2008). The 'text' level of the narratives, which is the description of the experiences, is presented in the plots below. Table 5.3 provides a list of the themes within each of the plots

Table 5 3: Emplotments title matrix

Fistula ordeal	Treatment process	Returning to life
<p>1. Fistula formation</p> <ul style="list-style-type: none"> a. Influence of others b. Geographical location & transport issues c. Poor health system 	<p>1. Surgical treatment</p> <ul style="list-style-type: none"> a. Immediate attempts b. Surgical repair attempts c. Sign of recovery <p>Post repair physical & health complications</p> <ul style="list-style-type: none"> - Persisting Incontinence issues - Sexual & reproductive - Post repair complications 	<ul style="list-style-type: none"> a. Defining 'returning to life' b. Facilitators of reintegration c. Barriers to reintegration
<p>2. Living with fistula</p> <ul style="list-style-type: none"> I. Challenges of living with fistula <ul style="list-style-type: none"> a. Physical & health b. Psychological c. Socio-economical II. Consequences on womanhood <ul style="list-style-type: none"> a. Stigma b. Child loss & childlessness c. Sexual Reproductive health d. Family living & relationships 	<p>2. Other treatment attempts</p> <ul style="list-style-type: none"> a. Traditional healers b. Over the counter medications 	

3. Coping with fistula a. Incontinence management b. Support network c. Spiritual coping	3. Support network in treatment - Informal support - EVVF support rehabilitation program a. Benefits b. Challenges	
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5.4 Fistula Ordeal

5.4.1 Fistula Formation

The stories on the birthing process provided an insight into what eventually resulted into the fistula formation. This process appears to signify the commencement of the sequence of events in the narratives, where the focal actor, the woman became embroiled in life changing events. The birthing experiences of each woman can best be described as horrific and traumatic; various issues were highlighted considered to be sign posts that demonstrated the role of various influences. The influencers in this context were either persons, or circumstances or structures considered to have had significant impact in the fistula formation. These influences began apparently during the pregnancy; for some women all the influencers had effect on their birthing experiences, while for others it was a case of one or two influences. However, overall, the influencers appeared to have interlinking effects on the birthing experience. Three main influencers were; Influence of others, geographical location and transport, and poor health system.

a. Influence of 'Others'

From the narratives, women even though they were the focal actors, appeared to be passive participants in the whole birthing process. The 'others' in the stories were persons that had an impact upon the process and outcome of birthing experience; they were family members and birth attendants. The birth attendants could be traditional or 'skilled'. The most prominent 'others' appear to be the family members. The family members were namely mothers/mother in laws or grandmothers, who appeared to be the traditional key players as females in birthing issues. Mothers/Mother-in -laws or

grandmother determined how and where birthing took place. For instance, their influence was obvious from the pregnancy period when issues surrounding where delivery should be, were decided without consideration to the woman's opinion, as demonstrated in Halima's story above.

The first choice for place of child delivery was the home. In the narratives, the preference for home delivery was influenced by cultural norms or financial limitations. In women's narratives, mother/mother in law or grandmother were named as enforcers of cultural norms concerning child birth. They also were responsible for decisions concerning seeking care during the birthing process when labour was not progressing successfully. Additionally, financial limitations were another strong reason influencing 'others' preference for home delivery. Financial constraints in families appeared to be a stronger determinant of home delivery. The practice of user fees for hospital services therefore limited access to health services. The 'others' were referred to as 'they' in women's narratives:

I used to see a doctor (ANC) and the doctor told me that the child was too big, and I need to be taken to the hospital when it is time for me to deliver. But because we have our culture like that of the Fulani, my parents came and took me from the town (Lagos) where we were staying to the village to deliver ... (Halima)

I couldn't take myself; they were the ones to take me...there was no money, they couldn't take me to the hospital when labour started (Asmau)

I was in labour for four days...my mother-in-law kept saying "why should I go to the hospital, women labour and give birth" ... It was the custom at that time in the village for women to give birth at home and there was no hospital... (Rose)

As a result of these influences, home delivery was the choice. Family members or birth attendants attended to labour; this could be traditional birth attendants (TBAs) or 'skilled birth' attendants (SBAs). The deliveries took place either in women's home or in the birth attendant's home. The birth attendants could employ diverse materials to aid labour from use of traditional remedies to orthodox medicine. Women described the

variety of assistance provided during their labour experiences, all with no positive outcome:

I spent four days in labour at home. A man was brought, they kept on putting hot water and pushing hand into my private part saying the baby was just close, but I was not able to deliver... (Christy)

They decided to let them try the local way, "she will deliver" ... so they brought a freshly hatched chick and added this to a concoction... that I will deliver right away, no way, they put a big wooden stick (used for stirring 'tuwo') in my mouth, and said that is how it is done. I will deliver right away... I could not urinate, and they even pounded and mixed a slimy vegetable and started pouring this into my front side to force the head of the baby out... (Rose)

I was in labour for three days. We called a 'doctor' and he gave me about three sachets of IV fluid at home, but nothing happened... (Patience)

The professional identity of SBAs called to assist in home delivery was unknown. Women referred to them as 'doctor' or 'person that worked in hospital'; they could not specifically identify whether they were midwives or medical doctors. On further query, they could only ascertain that they worked in the hospital. Patience (earlier mentioned above) referred to the person as a 'doctor' but later clarified he was a relative that worked in the hospital who offered to assist. For Patience and Christy, financial difficulties were not the reason for not seeking institutional delivery; Christy mentioned there was a prior agreement to pay for their services:

'An uncle' that was working in one clinic, when I started labour, he said he is going to try but if he fails, then we can go to the hospital. I am not sure of what work whether nurse or doctor... he works in the hospital (Patience)

(Laughing)...you know rural people... (more laughter) they went and brought someone- who they said work in the hospital. They kept putting in their hand, saying "she will deliver, she will deliver". He was to be paid. It was when the situation became critical; he finally said we should go the hospital (Christy)

In another vein, Fatima in her narrative attributed her delay in going to the hospital when labour commenced to her fear of surgical procedures; despite being in pain for five days. For her, no one was to blame for her calamity but again the presence of 'them' was obvious as her mother and a TBA supervised her labour. Sadly Fatima, unlike the other participants was able to influence her choice of place of child delivery to her own detriment:

I was in labour for 5 days before I was taken to the hospital and the boy was removed dead...There is a hospital in the village, but I was afraid of surgery that was why I didn't allow them to take me to the hospital...It was later when I became unconscious I was taken to the hospital. By then the child was already dead. It was my fault... (Fatima)

The labour at home before seeking medical assistance was between 1- 5 days. When all efforts failed in home delivery, the decision to seek care can be initiated by the birth attendant or by family members and not the woman. For births assisted by SBAs the decision for referral took place approximately after one day of labour. It is important to note here that the narratives on what transpired provides avenue of doubts on the professional competence of the birth attendants in identifying dangers signs during labour for prompt emergency obstetric assistance. Hence narratives on deliveries in homes attended by 'skilled' attendants create a picture of the kind of practice in the rural areas:

The man (works in hospital) ... tried all night and he gave me injection and IVF... nothing happened... in the morning when he couldn't handle it I was transferred to Plateau Hospital where I had C/S (Talatu).

I was suffering... that night the pain became unbearable and I cried out, "oh my God! I am dead!" My mother joined me and started crying. After trying and trying, the 'doctor' decided that I should be taken to the hospital... (Patience).

On the other hand, however, for women assisted by TBAs, decision to seek institutional attention occurred after longer periods of days, between two to five days. This decision was often taken by another family member pressurising the 'influential' person to see

reason. Seeking care for one woman resulted after the intervention of the natal family; another woman lamented/reasoned that the absence of her mother contributed to her ordeal. The TBAs undoubtedly as expected did not possess the ability to detect danger signs indicative of complications. They were more determined in providing birthing assistance in their usual manner of practice regardless, being oblivious of the outcome of their continued delay to seek medical care:

The people in my family house did not even know I was in labour until after four days. It was after these four days they sent for them. The woman that nursed me as a child was the one that insisted I should be taken to the hospital.... the mother of my husband said, no way! She is going to deliver at home. I was then taken to the hospital (Rose)

I spent three days at home in labour before I was taken to the hospital in the village (Zing). I think she (mother) might have stopped the woman that they called from pushing her hand inside me, because I think that is one of the reasons I started leaking urine. She kept poking her hands inside... (Alheri)

My mother was not home when I started labour on Tuesday. She returned on Wednesday, she was the one that insisted that I needed to be taken to the hospital (Halima)

b. Geographical Location and Transport Issues

All the women except one lived in rural locations in the northern parts of Nigeria (See table 5.1 in Demographic information p.162). However, for the only woman (Halima) who lived in the city, the incident occurred in a rural location in north west Nigeria; as earlier mentioned due to their cultural practices, Halima's parents had taken her back home to a rural location for her child delivery. On the whole living in the rural geographical location meant either the absence of hospitals or hospitals with no capacity to provide the required assistance. Furthermore, due to geographical remoteness, transportation was an issue; hence some women experienced further delays in receiving the necessary intervention. For instance, 'only one motor vehicle in the village', or women had to be transported by some hazardous means like motor bikes for Loveth or wheelbarrow as in the case of Rose:

Our village is off the road, there is only one vehicle in the village. They went to get the vehicle, but we were told that he has gone out with passengers. He did not come back until around 9:30 PM. That is when they took me to the clinic in our village which was very small...they told us that I cannot give birth there, that I should be taken to a bigger hospital in Kano city (Halima).

...since we are in the village (there is no hospital at that time) there is no car, they took me with the wheelbarrow to Potiskum to where the hospital is in my state [province] (Rose)

The influence of geographical location on fistula formation was made more apparent and significant with women who sought immediate institutional delivery at the onset of labour. These women experienced serious delays in accessing care despite efforts made to seek care early. Three out of the fifteen women reported going into the hospital, at the onset of labour. But even in these cases, women again had to face the additional hurdles of moving from one hospital to another and only finally received the required emergency obstetric care at an urban hospital:

I started feeling pains in my stomach, so I went to the hospital that same day. When I entered the hospital, they said, "See, the boy is coming out". The boy started coming out head first, that was around 4 p.m. When the head came out, it stopped there..... it neither came out nor went back in. There is no doctor in that hospital... The whole nurses spent that night on me... They asked us to go into the hospital in town after this...Our road was bad then, so they put me on a motorcycle (Loveth)

I started labour at around 10pm... I was first taken to the kanga hospital when they couldn't handle it, I was moved to Sauki hospital and when that one couldn't work too, I was moved to the specialist hospital (urban location). Many doctors were called but couldn't deliver me, so I was taken to the theatre... (Gladys)

c. Poor Healthcare System

Another influence on fistula formation was the issue of poor healthcare systems in rural facilities. In the context of these narratives the poor healthcare system was considered with reference to ease of immediate access to required care on arrival at a health facility; the availability of staff, and capacity (infrastructure) to provide emergency obstetric care at health facilities to address the obstructed labour; and, affordability of the services. Interestingly only one woman received immediate emergency obstetric care. This was provided at an urban health facility. However, for majority, even at the health facility there were further delays. The reasons for these delays were different for each woman; in addition to those described above by Gladys, strike action in hospital by health workers, and arrival on a non-working day (weekend). Another significant determinant of access to care was the issue of user fees for services rendered at facilities. Due to financial limitations women were unable to pay for a C-Section; care was only provided after negotiations with the doctors. The highlighted issues casts' doubts on equitable health service provision in the rural areas. Women narrate their encounter:

When we got to the hospital...we were told they were on strike I spent the night there and, in the morning, they told us to go to a private hospital in Gombe (urban area) ...(Maimuna).

As we got to the hospital it was a Sunday and they said no way, I had to wait till the next day before coming and I waited in pain till Monday (Rose)

By the time we reached Saminaka, my vagina was already swollen so they said, there is no way I can deliver on my own, they will have to operate, and we will have to put money down before the surgery. My husband had no money; my mother had no money... They insisted they must provide the money...My mother spent the whole day in Saminaka looking for money among relatives but couldn't get anything. She came back and begged the doctor and the surgery was done around 12 pm the next day (Loveth).

The health system was also rated based on the quality of services provided. Narratives described incidences that appear to be unwholesome practices. A woman narrated a

tale of negligence; where health workers delayed for 10 hours in calling for the doctor despite being instructed to do so after 30 minutes. There were also tales of procedures carried out in evacuating the baby that women believed were the causes of their fistula developing. Women described what transpired:

It was then a nurse in the hospital said she was going to sit on me here (touched her chest) to make the baby come out, I told her, "...you want to kill me". She said it's because of my stubbornness something bad will happen to me. The next thing I was looking at the machine, lying down... I heard the noise of a machine that they used to pull out the baby...grrrrrrrrrrrrrl... What I knew next was urine...and stool (Rose)

One of the doctors said since they are not going to operate, they should at least try to remove the child because the child as of that time was already dead. So, one woman climbs on top of me and was pushing and squeezing while the doctor had his hand in my private part and the two of them were struggling to remove the baby. At last they succeeded in removing the baby by force..., his body was already looking decomposed... (Halima)

When we got to the hospital, the doctor examined me and instructed the nurses that if I didn't deliver in thirty minutes, they should go and call him...We got to the hospital around ten in the morning and we were there till 8pm in the night before they went to call the doctor. The doctor was furious; he told them that they have killed me, saying that his instructions were if I didn't deliver in thirty minutes, they should call him. He told them to take me to the theatre, but they kept pushing the responsibility to each other, so I walked gently to the theatre where I had surgery (Patience).

In summary the narratives provide a graphical description of the hurdles women faced and the role of influences on the birthing experience that led to fistula formation.

5.4.2 Living with Fistula

The commencement of uncontrollable incontinence after the failed delivery was a confusing and life changing experience. Leakage experienced was mostly urine, however

five out of the fifteen women experienced both faecal and urine leakages. The time of onset of leak varied for women, some observed it was immediately after delivery while for some it occurred after some days. The experiences of living with fistula will be discussed under the challenges the ensuing incontinence imposed, the specific losses experienced as a woman and the coping mechanisms adapted.

Challenges of Living with Fistula

The changes that incontinence wrought affected every facet of life and living experiences; the difficulties faced were numerous and are discussed as challenges of living with fistula. The challenges were namely: physical and health, psychological, social and economic. It is pertinent to note that the challenges are interlinked and interwoven, one challenge stimulating another, presenting as an intertwining complex maze (see figure 8 below). The commencement of leakage spearheaded the physical challenge of wetness and smell of incontinence, which invariably affected the psychological, which in turn affected the social, economic and spiritual facets of women's lives. Each of which had impact upon the other.

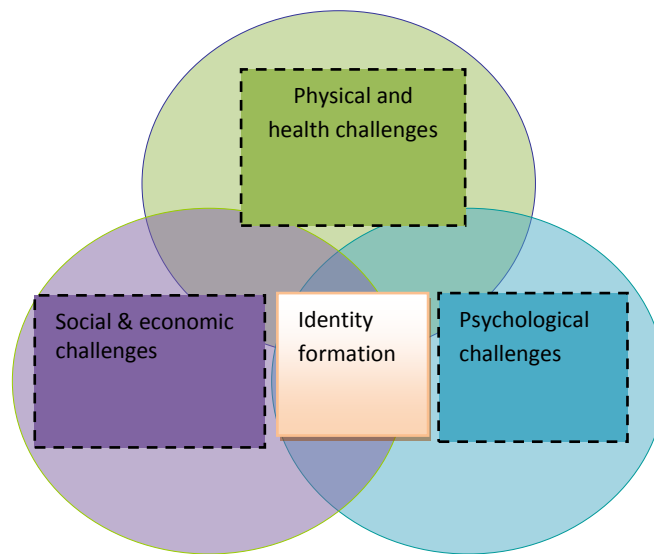


Figure 8: Interplay of challenges of living with fistula

- Physical and Health Challenges

The wetness and smell from the uncontrollable incontinence created a series of physical challenges that could be termed as physical barriers to normal daily living. These physical barriers defined who they were, the normal day-to-day activities they could participate in, and even where women could go. As captured by Christy in her narrative “I knew I smelt because of the urine leaking so I did not want to go into the midst of people”. Additionally, due to the uncontrollable incontinence flow of urine and/or faeces the challenges of maintaining hygiene was enormous. Invariably all of these issues affected the social life contributing to psychological trauma, as women tried to come to terms and manage the changes.

At the time I was having serious leakage, I was washing every minute... no rest...day and night I was burdened with washing because of the leakage. Even

food...sometimes people cannot even eat the food I cooked...who will eat the food of a woman leaking urine? (Alheri)

I actually was saying it could have been better if I were dead. At that time, it was a big challenge...You have to deal with people, deal with your smell, even going to church was no longer a thing to look forward to. If I go at all, I will sit at the back... I said to myself death is better than that kind of life... I was smelling so much... (Asmau)

There were also cases of post-delivery surgical complications, which resulted in prolonged hospital stays that stretched for days or months. Upon discharge home from the hospital after the failed childbirth experiences, family had to nurse women back to health. These compounded the physical challenges of incontinence thereby aggravating an already difficult situation. Again, for some women there were additional physical health difficulties caused by prolonged labour, which is referred to as 'the obstructed labour injury complex' (Arrowsmith et al., 1996). These are recognised 'field injuries' that developed as a result of the obstructed labour affecting the pelvic area. These are listed as urologic, gynaecologic, gastrointestinal, neurologic, musculoskeletal, dermatologic and foetal injuries (Arrowsmith et al, 1996). In the narratives, majority of women narrated they had difficulties with walking after fistula developed. Foot drop is one of the neurological injuries in the injury complex. The inability to walk further restricted movement thereby worsening self-isolation:

With urine pouring out without control we came back home... I had this very serious pain in my legs that I could not walk, I could only crawl on my buttocks, for up to eight months...life was no longer the same... If you have VVF it restricts everything about you... (Maimuna).

With the problem of the operation wound...I was discharged home...leaking, doctor thought I wouldn't live... my people started applying hot water on me. One month, two months, I started sitting up, like child's play... Little by little I started putting my legs on the ground. (Loveth)

...at that time... I had this problem I was not able to go to church, go to farm or interact with people... honestly the condition I found myself in. When it started, I was not able to use my two legs; I started walking after about two years... I was the only one with the problem in the whole village; I find it very difficult to associate with people, leaking urine... (Talatu).

- Psychological Challenges

The experience of living with incontinence stimulated psychological trauma for women and all the woman expressed negative feelings about their predicament. This was particularly made worse by the fact that, the condition was an unknown to them, to family and in the community. This precipitated the feelings of shame, vulnerability and loneliness, causing some 'soul searching' reflection; some viewed their experiences as punishment for 'sins' committed and as a way of learning lessons.

The pains and difficulties faced caused women to wish for death. Two women reported suicidal ideation, and Christy narrated her experience in her botched attempt to end her life:

I kept thinking...and I said "ha! God what did I do to deserve what I have become..., if it is a result of some wrongs that I have committed forgive me, but if you see it is necessary sometimes for my body to experience pain... I thank you God..." (Talatu)

At the initial stage of this problem, I felt all alone on the planet earth, at a point, I opened my mouth and told my elder brother that I am going to take poison and end my life. I said, "It is better for me to end my life than to live with this kind of problem" (Alheri)

I was always thinking.... I thought so much.... I called for death so many times...I didn't know anyone in the village with that kind of a sickness... There was a day I tried to kill myself by drinking cement mixture... I did this because of the way I felt about my sickness... (Christy)

The loss of self-control over continence flow that is associated and acceptable for infants - but not for adult women - was noted by Halima, triggered emotional turmoil. Another

significant psychological consequence of the leakage was that women engaged in re-evaluating who they were and redefining their identity. The leakage conferred on women the feeling of an identity defined by the leakage. Women viewed this new self as a person that had lost value primarily in terms of a reduction of who they were as women. There was also recognition of the new self as totally different from whom they really were. Women narrated how the changes impacted upon their self-worth and dignity as women:

...I did experience many changes and challenges that sometimes will make me cry and sometimes prevents me from sleeping... A grown-up woman like me and not a baby waking up in wet rags every day is really a problem (Halima)

I used to see myself as someone whose value has reduced... my value as a woman has reduced...my life has been cut short... (Maimuna).

I feel I am now different from the way I used to be ...I feel I am different from how God created me...surely the condition had reduced my worth...(Sarah)

- Social and Economic Challenges

Another untoward consequence of the leakage was its effect upon social and economic livelihood. Expectedly for most women the incontinence flow limited socialising and restricted movements; this invariably resulted in isolation and feeling of self-consciousness. This in turn impacted upon their ability to source for means of livelihood. Additionally, the health challenges faced made engaging in any physical strenuous activity extremely difficult; particularly more so for women who were mainly subsistence farmers, an activity that requires more physical manpower. Consequently, women became dependent on family and community members for daily survival:

I felt very bad because I am no longer free, I cannot sit among people. Even if I attend a gathering, I cannot stay there for a long time and I cannot sit down...I was completely dependent on what people gives me, if nobody gave me anything there is no way I can help myself... (Patience)

Going to the farm wasn't comfortable...If I sit down...If I tried to work a little, my waist down will be paining as if it is going to fall out, I will just have to give up

working and go home. I was unable to do anything... (Long pause) I had no food..., I will send my daughter to my parents who will help me. At a point they were saying if I cannot cope, I should return home. (Asmau)

Even before I got the problem, he wasn't bringing any food; I was the one doing everything... food...soap, I will have to be the one to look for it and then this thing happened... The reason why I wasn't happy...being that when I was strong, I could get up and scout for things that will help me but now I don't have the strength to help myself...I had to rely on people in my neighbourhood to even feed myself and my children... (Tlatu)

Consequences of Fistula Development on Womanhood

Developing fistula and living with it, had profound effect upon women. This effect bordered on the new identity women now possess and was a product of stigmatisation. The consequences of fistula development include child loss and childlessness, sexual and reproductive health issues, and family living and relationship difficulties. Each of these consequences had interlinking impact upon each other (see figure 9 below).

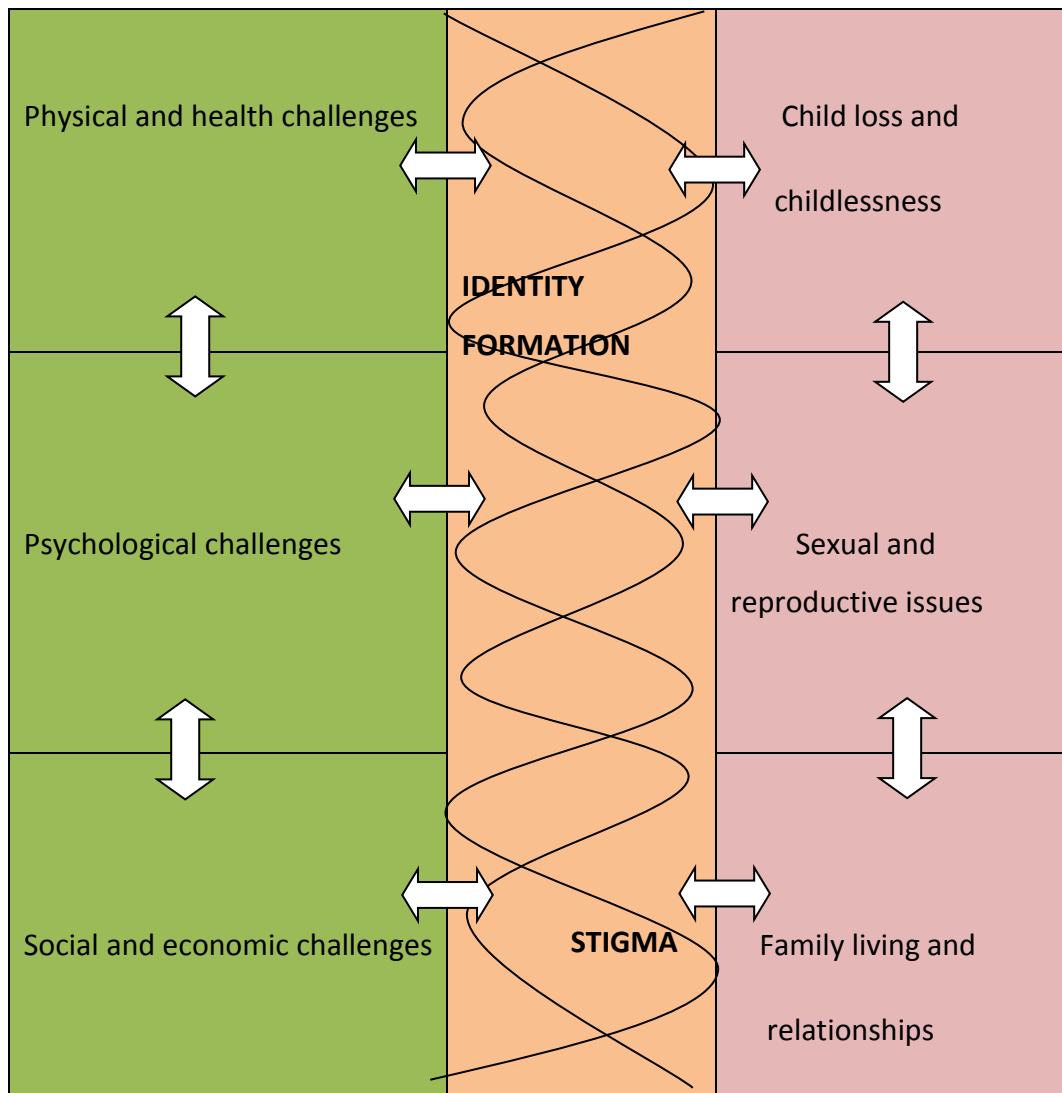


Figure 9: Interlinking consequences of fistula development

- Stigma issues

One of the most striking consequences of fistula was stigmatisation. Stigmatisation was on two levels, self-stigmatisation and stigmatisation by others. Firstly, was the self-consciousness/awareness of urine leak as earlier described, stimulated by the identity formation. This made women purposely limit their association with people, resulting in self-stigmatisation; mainly stimulated by the fear of the negative attitudes from people, or through embarrassment because of the leakage. Women that claimed they did not experience stigmatisation were observed to subject themselves to self-stigmatisation:

No one ran away from me, I... was running away from people... (Laughed) I knew my condition (Christy)

Ceremonies were no go areas for me because of the restriction caused by urine... Even though I do take care of it ...but I kept feeling that something might go wrong, and I will be disgraced so I avoid public places... (Maimuna)

The second level of stigmatisation is that by others; evidenced by negative treatment on individual, family or community levels. This could be by spouses, or family or community members. Importantly, the negative treatments were not in every case and persons involved in carrying out this behaviour also varied. None of the women experienced negative treatment from both family and community members, but acts could come from either family or community members:

My brothers supported me...but... my sister in-law in the same house... hated me because of VVF, which was why I was praying that it was better God, took my life...If she keeps water in a clay pot. She doesn't want me to put my "urine-soaked hands" into her pot. It was like she saw me... that I had become an object of ...no value... (Gladys)

After some time, my people left me... They were tired... I was frying chin-chin and people use to patronize me so that was how I used to put together my transport money. I didn't experience any stigmatisation... if they have done that, I wouldn't have known what my life could have been like today... My household items were distributed by relations among themselves as if I was dead...they distributed everything... "When is she going to get up and do something?" If I want to take a dish to mix my chin inside, they will ask me to go and buy my own dish. If I touch that pot, they will ask me to buy my own pot (Loveth)

Again, due to hygiene concerns around their incontinence status women reported family members refusing food cooked by them and being denied communal plate sharing while eating. Women narrated their experiences:

Even food...sometimes people cannot even eat the food I cooked, and they will say who will eat the food of a woman leaking urine? (Alheri)

...one of the women in the compound told me one day that I should not cook when visitors come, because they might not be 'able' to eat the food...(Margaret)

Some will refuse to eat food with me... because I was leaking urine (Fatima)

Some of the reported acts of stigmatisation by family appeared to border on the perceived 'loss of value' as a woman in the family. For instance, in the case of Patience, her in law's negative attitude changed after her successful child delivery after her repair:

My husband and father's family supported me even neighbours, but I had problems with some of my husband's relations; like his mother...she kept saying that her son is spending so much money on my treatment. His siblings...they were really hostile towards me... saying all manner of things...Just like what my mother in law had said... "See what she has become" ...I was no longer of any value and yet their brother was wasting his money on me...she only started visiting again after I had my baby after my cure... (Patience)

Overall, women appeared to have one form of support to mitigate the stigmatisation experienced; this could either be from family (primarily natal family) or community. However, despite this support, the stigmatising behaviours triggered psychological trauma in women. However, reaction of defiance to people's negative attitude was also sometimes reported. Two women narrated their separate experiences:

Yes, I do go out with it like that... it was like that... I will stand up without hiding it because everyone knows I am sick...I did not hear it from them, but I hear that people are saying that I smell and all sort of things (Nanchit)

If you enter a vehicle with this problem, you will hear people saying, "There is smell of urine around here." I will just sit down and keep quiet. It reached a point that one day as they were talking, I opened my mouth and told them that I am the one and I got it as a result of child birth not that I bought it from the market (Rose).

Another dimension to the stigma issues was a case of family member directly involved in care - giving being subjected to stigmatisation by other family members. Family

members usually would assist in daily chores such as maintenance of hygiene and cooking of meals, particularly when women were still incapacitated during the initial period. Rose narrated her experience:

My mother suffered more in all these; she was always in urine and stool, because of washing every day. It was so bad that in our compound, my mother's co wife refused for her to cook for the family... no one will eat food cooked by her because they said she was always in urine and stool. She was always washing my urine and stool. The woman said "never!" She will not eat food cooked by my mother. She was told just to concentrate on caring for me, so she stopped cooking totally... (Rose)

On the contrary, two women narrated receiving acceptance from both family members and neighbours. Maimuna believed her experience might be connected with the fact that no one apart from her spouse and co-wife were aware of her condition. Moreover, Christy's social isolation of not going out, might have spared her from experiencing stigmatisation in the community. These can be described as premeditated attempts at concealing an 'offensive' identity. Both actions were protective measures against acts of communal stigmatisation:

I don't have any problems with my neighbours or co-wife...The neighbours didn't know that I had a problem... They see me healthy... Even my mother-in-law doesn't know, it was only my husband and my co-wife that knew I had the problem...the compound is a big one...except when I tell them I want to travel, they would ask "you are still not well" ...but they don't know exactly what is wrong with me...but my co-wife knows... and when I hang out my rags, she helps to bring them in... (Maimuna)

My family treated me very well, I did not go out... I did not want to go anywhere...when the condition developed... not even to church until when I got healed... (Christy).

- Child loss and Childlessness

Foetal injury is one of the field injuries described in the 'obstructed labour injury complex' (Arrowsmith et al, 1996). Expectedly, the outcome of delivery was mainly still birth; however, two women out of the 15 women interviewed had live deliveries. The additional trauma of child loss was evident in some of the narratives, this was more apparent for primigravida women that remained childless even after several repairs as in the cases of Alheri and Sarah:

The baby was dead...They didn't tell me that the boy was removed dead and I was seeing all the other women with their children so when my senses began to come back, I started asking my sister in-law where my boy was and she said I should not worry...Up to this moment, nobody came out to tell me that my baby was removed dead except what my spirit told me (Sarah)

I felt very sad...I was told part of the baby's body was already going rotten...I feel sad considering all the troubles I went through in carrying the pregnancy and the delivery...I feel very sad when I see all my mates that we were pregnant at the same time with their own children...it is very painful for me... (Alheri)

Child loss and childlessness contributed to stigma related issues within families, and some women reported family disruptions as a consequence of this. For instance, both Halima's and Sarah's spouses married additional wives, after they developed fistula. Both women believed their condition contributed to their spouses' additional marriage, equally they attributed the stigmatisation they face from their co-wives to their childless conditions (discussed further in section below):

I faced challenges as a woman that no one should face, because of my condition my husband married another wife, and so I have a co-wife... (Halima).

- Sexual and Reproductive Health issues

Another consequence of fistula was its negative impact upon sexual and reproductive activity. This is also part of the 'obstructed labour injury complex' (Arrowsmith et al, 1996). In the narratives, sexual difficulties were more prominent among the married. Difficulties described were namely, cessation of sexual activity due to hygiene issues,

penetration difficulties, and leakage during intercourse. For some women, sexual activities ceased abruptly after the commencement of the leakage. Cessation of sexual activity was displayed by their partner's change of attitude towards them sexually and by the change in sleeping arrangements. As Margaret narrated:

He never... he never wanted to come near me (sexual intercourse) again.... If he wants to come inside the room, he might come in and leave immediately ... I was no longer allowed to sleep on the bed I was made to sleep on the floor because they said I would destroy the mattress with my urine...

Contrariwise however, three women among the still married reported no impact on their sexual activity; the partners appeared unperturbed by the leakage. Nanchit conceived despite the fistula:

He doesn't say anything about the leak during sex...I got this problem during my first delivery but despite the urine leakage, we have had two more children with him... with the urine pouring... (Nanchit, pre- repair).

On the other hand, the single and also the divorced/separated women reported loss of sexual desires and total cessation of sexual activity since developing fistula. This was attributed to the psychological trauma faced and because of the ill treatment experienced. Another reason for loss of sexual desire was the fear of fistula recurrence as a result of pregnancy. Christy, who had a diversion repair, her response appeared terse, "I tell.... anyone that comes to me to have any relationship about my problem. So that they can 'clear' off immediately if they cannot stand it". Therefore, single and divorced/separated women were not willing to engage in any future sexual/ marital relationship with men:

VVF killed my desire for marriage to the extent that I don't see anything good coming out of such relationships...No, I am not interested in sex.... It has killed my desire for it totally...also the fear...I believe that if I become pregnant I will get VVF again (Gladys, single)

I don't value men now... I have lost any feelings for men...I don't even want to see them...I might get VVF and then be abandoned like my husband (Damaris, divorced)

Taking all these issues into account, sexual and reproductive health issues were burdensome to majority of the married women, and the loss of sexual desire by their spouses was deemed to have signalled rejection of their body now considered offensive. Damaris captured her feelings:

I was not happy...so because of my condition he no longer wants me; I have become offensive to him now that to even greet me was a problem talk less of sex (Damaris)

On the contrary, Asmau's effort to use her spouse's sexual advances to negotiate for assistance to seek cure was stiffly rebuffed. In her own case, her body was not offensive; he was willing to tolerate the leak as long as Asmau fulfils her duty to satisfy his sexual desires. Her shrinking from this duty was tantamount to punishment that led to her being asked to leave her home:

When the girl that I gave birth to started walking, he began to come close (for sex) I told him that I cannot... because of the problem I have. I asked him to help me check for another hospital, but he said he will rather go and look for another wife that he will not continue to suffer because of me... he went and married another woman saying he is not bothered, that I should go and leave his house because I am useless in the house (Asmau)

- Family Living and Relationships

One of the consequences of the physical, psychological, social and economic effects of fistula was a strained family relationship. In some of the cases, the strain was further worsened by the sexual and reproductive difficulties (as earlier highlighted). Generally, in the majority, this led to either a separation or divorce (table 5.1). Nevertheless, two women reported overwhelming support from their spouses, one of these women (Nanchit) still has persisting incontinence despite repairs. The timing for separations or divorce differed, for two women this happened immediately while they were still in the

hospital on development of fistula, while for most of the other married women the strain in relationship developed over a period time ranging from few months to years while seeking for a cure:

I was just staying like that until one Sunday... he said he can no longer stay with me. The room smells, and people cannot come for a visit in the house. I said, it is ok, I know my parents will not reject me. I started parking my things with the help of his mother (Margaret)

Ha! My husband's house...I have not set my foot there since I was taken on a Tuesday for delivery with the wheelbarrow to the hospital..., till today since I left the house I have not gone back to his house. Ha! It was in my house he sent my papers [divorce] (Rose)

Returning to their natal family home was the usual option when women face rejection or abandonment by spouses. However, in some cases as earlier discussed women were not sent away from their matrimonial homes, instead their husbands married a second wife. Polygamy is an acceptable practice in some of the cultures; hence the development of fistula provided the impetus for men to seek another wife. Women expressed feelings of frustration over the addition of another wife and the deterioration in their own marital relations. Furthermore, the presence of a co-wife (except for one woman, earlier mentioned) significantly worsened the strain in marital relationship:

Looking at my situation I can say VVF has caused big problems for me because it has separated me from my husband and I don't know whether he is coming back or not... honestly, I am really sad, very sad. It is not easy for a woman to be married and then go back and stay with her parents... it is not easy... I am not happy (Talatu)

I was wondering why he (husband) can't be patient for me to get better, come back and get back to my room... we were living in the same house with my co-wife and the life wasn't pleasant, there was jesting, mockery and the rest...That was before he got me my own house. Initially we were living together... we started having problem... (Halima)

Interestingly but what appears to be a strange twist, Fatima used her fistula experience to escape from an unhappy marriage. Fistula formation provided an opportunity to begin a new life:

I really wasn't in love with that first man and even the money we used during my stay in hospital at home, was money I had to raise myself, he wasn't taking proper care of me so when I got this problem, I said I will not go back to him. My people wanted me to return to him, but I refused (Fatima)

5.4.3 Coping with Fistula

- Incontinence Management

To contain the incontinence flow, women devised different coping techniques; use of rags was commonly reported. Women wore rags as paddings to catch the incontinence flow. For women that isolated themselves physically from contact with people, rags were also used to pad seats to prevent them from becoming soiled.

I spent most of my time inside the house, for three years... I was being encouraged to step out and once in a while I will come out of the house... I picked the old clothes my brothers were using to go farm that were already worn out and washed them for the rags I was using. (Gladys)

Rag use however, created difficulties for some women; these included the physical and health challenges of skin rashes, and the social challenges of embarrassments from leaking or falling rags. The thoughts of these situations caused anxiety and as such some women did not venture outside, thus again perpetuating social isolation. Other difficulties were sourcing and maintaining hygiene with rag use. These challenges were mainly that of not having enough rags to use particularly during wet weather when wetness prevents washed rags drying up and stocking up when rags wear out. Hence women had to develop ways to manage their rags judiciously to cope with the difficulties:

I had plenty of rashes... it was so painful... so I used to rub pomade by the side (Nanchit)

Initially I used rags, but because it could not control the flow, I started using my wrappers, I had to use a one whole wrapper, and in spite of that I would still get soaked. So, I had to be changing them often. It got to the extent that I had to start using my elder sister's wrappers when all mine was worn out... (Alheri)

No, I wasn't going out, I was just sitting at home. I was even afraid of going to church, the fear of my rag dropping in the midst of people and the fear of standing up to find myself all wet in public (Sarah).

I was using rags but sometimes if I am at home I will not use them because of itchy rashes and pains and because of the stool... I will only wrap my wrapper and the wrappers don't last, they get torn because of the urine... (Asmau)

Disposable diapers even though the best alternative to minimise the difficulties with rag use, were not widely used. Only Fatima and Maimuna reported the use of disposable diapers, but this was not on all occasions due to the financial implication. Fatima and Maimuna described the additional benefits they enjoyed, which mainly consisted around the lack of constraints in time spent outside of the home without the fear of soiling. As for Maimuna, disposable diapers effective continence control meant a properly concealed identity since the restriction of length of stay outside of the home is removed. Both women however complained of the high cost hence limiting its usage:

It was when we discovered pampers... Then I started using pampers and rags that was when I can enter everywhere. But pampers was not every day because of the cost... (Fatima)

If I buy pampers... If I put it on, I can spend a long time outside if necessary... I can spend a long time till I return home, nobody knows... I can spend a long time like everyone else... no one knows I have a problem... pampers helped me, except it is costly... (Maimuna).

Two women described other strategies adapted and their struggles to cope with the incontinence. Margaret reported restriction of water intake, which was non-effective, while Maimuna turned to her radio for diversion from perplexing thought patterns:

Even though I stopped drinking water, the urine was still rushing out... (Margaret)

... I sit with my 'entertaining friend' (radio) listening to all that is going on around the world beyond my village while I am sewing... I am always with a radio... so that I will not be thinking of different things ...they said thinking can cause another sickness...so I better stop it...I am still struggling with the urine leak, let me not add more to my condition...that is why I am always with my radio (Maimuna).

- Support network

One of the key ways women coped with living with fistula before accessing treatment was through their support network. This support network was made up of family, friends, and community members; community groups or individual. The support provided varied from, care provision to financial support, provision of food and companionship, to providing basics items needed in maintaining hygiene. The financial support was majorly instrumental in accessing treatment. Some women narrated:

When I got this problem, my parents and my friends were very worried. Sometimes they buy things like soap, perfume, and powder for me so that I can bath and spray it around to reduce the smell. The relationship was pleasant... (Patience)

There is a woman in our neighbourhood who sent her daughter to go and fetch water for me. Our water source is very far...and that same woman prepared pap in a big container and brought to me (Gladys).

My father sold his land and part of his house to get money. My seniors also helped because their goats were sold, some of their farmlands were sold. All the money was spent in that hospital in Maiduguri... (Rose)

- Spiritual/ Religious Coping

Religious coping through spiritual consolation played a significant part of women's narration in coping with living with incontinence. In managing the psychological trauma, spiritual coping techniques involving reorienting feeling of despair to divine

judgement/will or acceptance of condition in comparison to others they believed to be worse off. Another was, seeking forgiveness for negative thoughts or acts that might have resulted in the calamity of fistula. These could be through thought processing and self-affirmation of faith in God's help.

I have never thought of offending God by wishing I was dead, I had the belief that I will get well by the help of God (Damaris)

The thoughts that came to my mind were.... I kept thinking... and I said "ha! God what did I do to deserve what I have become..., if it is a result of some wrongs that I have committed forgive me and if it wasn't, but you see it is necessary sometimes for my body to experience pain... I thank you God..." (Talatu)

I had different thoughts...when you have problems; surely you have all manner of thoughts that must offended God I can only ask for God's forgiveness ...one spirit in me was telling me I should not worry, I am not the only one in this condition and just as God calmed the storms so will he make a way for you (Sarah)

Sometimes I use to encourage myself by saying things like that can happen, so that one will correct some of his wrongs... (Patience)

5.5 Treatment Process

5.5.1 Surgical Treatment

a. Immediate Cure Attempt

Remedying the situation was paramount for all the women, but the process of seeking care was neither straightforward nor an easy experience. Only one woman (Halima) received immediate but unsuccessful repairs at the hospital where delivery was done, others received referrals to repair centres. As Alheri related in her narrative:

We were sent to Yola and the people there said they cannot do it, so they sent us to Maiduguri. I went to Maiduguri where I had surgery but if I sit down, the urine and stool will be pouring out as if nothing was done I was there for six months...so I came back home...we later heard about Akwa Ibom... I went there had

surgery...the stool stopped but not the urine...there we went up and down for months...no results...I returned home to wait for 3 years...

Period of waiting and receiving treatment varied from three months to 15 years. On the other hand, some women despite information on the repair centre experienced difficulties in going immediately for treatment. The delays were mainly due to financial difficulties, even though repairs are done at no cost to patients at designated repair centres. At the initial point, women were mostly unaware of the cost-free treatment. Meanwhile some other women had no information on how to access treatment. Consequently, some women carried on living with the condition:

One of my aunts that is working somewhere came and advised that I should be taken somewhere for treatment, but my people said they have no money and they were saying that I was still weak from the surgery I had gone through that they should wait until I am stronger. I was there with it...waiting for them to have enough money, I was there with the condition from 2005 till 2007 I was living with the leaking urine for three years (Gloria)

b. Surgical Repair Attempts

Gaining access for treatment was also facilitated by information provided by fistula survivors or visitors from the town. In her narrative, Fatima related “a woman that came here got treated and was now well met my mother... it was that woman that brought us here”. In Nanchit’s narrative, “We got the news from a woman that was here. When she went back home... she told us... that they do this type of work”. However, getting to the repair centre was not an easy task in terms of financing the transport cost; women therefore had to desperately seek for financial assistance from family members:

My brother told me he is tired, we don't have a father, we don't have a mother and he is the only one and now he is tired. I told him that you are not alone.... since God has given the energy to farm, I will farm and whatever I am able to gather, we will put together so that I will be able to seek medical attention. That is how I was able to come to Jos (Alheri)

He (husband) said he doesn't have any money to give me. So, I presented my case to my parents who gathered some money and gave me that is the money I used to come to Jos... (Asamu)

Out of the 15 women, only Damaris related hearing about the centre from a radio announcement and receiving government financial assistance to cover the travel cost to the centre for repair with other women. The EVVF centre's outreach to neighbouring states organized in collaboration with the state government created an opportunity for Damaris to access treatment:

...listening to the radio and we heard them announcing that some people are coming to operate on those that are leaking urine. Those that were leaking urine were asked to report to that General hospital. I went there and had another surgery...it was the people from here...but it failed so we were told that those that were not completely healed will be brought here. The state government provided each one of us, eight thousand Naira as transport fare to and from Jos (Damaris)

Women had an average between one to seven repair attempts (Table 5.4). The repair attempts yielded different degrees of success; success measured by women as 'becoming dry'; no more leakages. Five of the women had had repair attempts at various locations before coming to the EVVF centre. Even for some, it took additional repair attempts at EVVF centre to become dry, while some remained incontinent despite these repairs. Seven women considered themselves to be dry, five had mild leak, one very mild leak and two had severe leak.

Table 5.4: Incontinence and repair information

Name‡	Type of fistula	Period of living with fistula before 1 st repair	Total period of living with fistula	Source of information on EVVF repair centre	Number of Repairs		Period since last repair	Current continence status:
					Others	EVVF centre		
1. Margaret	VVF	1year	1 year	Clinic staff	Nil	1	3years	Dry
2. Rose	RVF&VVF	6years	22 years	Fistula survivor	1	6	8 Months	Very mild leak
3. Damaris	VVF	6months	7 years	Radio announcement	1	4	4 years	Dry
4. Christy	RVF & VVF	3months	2 years	Hospital referral	Nil	5	8 years	Dry
5. Alheri	RVF & VVF	6months	12 years	Fistula survivor	3	2	12 years	Mild leak
6. Patience	VVF	3 months	7 months	Spouse inquired from friends	Nil	2	10 years	Dry
7. Asmau	RVF & VVF	10 years	10 years	Visitor from repair centre town	1	1	4years	Dry
8. Sarah	VVF	3 months	3 years	Referral	Nil	3	5 years	Dry
9. Halima	VVF	1month	22 years	Self-referral; information from friends	4	3	5 months	Severe leak
10. Talatu	VVF	4 months	10 years	Hospital referral	Nil	5	9 years	Mild leak
11. Nanchit	VVF	15 years	23 years	Staff of repair centre	Nil	4	8 years	Mild leak
12. Loveth	VVF	4 months	15 years	Hospital referral	Nil	2	15 years	Mild leak
13. Gladys	VVF	3years	4 years	Fistula survivor spoke to family member	Nil	3	5years	Dry
14. Fatima	VVF	3months	7.5 years	Fistula survivor	Nil	3	7 years	Mild leak
15. Maimuna	VVF	8 months	15 years	Fistula survivor	Nil	4	14 years	Severe leak

‡ Pseudonym

c. Sign of Recovery After Repair

Generally, women believed signs of cure after repair resulting in them not having to endure “urine washing the back of my leg” or “stand without fear” were signs of cure. Margaret who had a single repair and became dry, joyously stated “I kept touching myself thinking, so now I can urinate by myself, I have been discharged.” Even for women that still had some forms of leaks; on their part they were still able to explain what signs were evident to prove recovery. Generally, women associated signs of recovery to be: discontinuation of rag usage, ability to feel the urge to urinate when asleep and pass urine at will, and unrestricted movements. Whilst others, referred to their ability travel to a certain distance before using the toilet as a sign of recovery:

I don't use rags again, the only problem is when I feel like urinating, before I could reach the bathroom, it will start leaking out...I can reach Pankshin (2 hours journey) before I tell them that I want to urinate... (Nanchit: Incontinence Status- Mild Leak)

The evidence is that even when I am deeply asleep, I can feel it when my bladder is full. Before my last surgery, that wasn't the case...I go to farm, I go to conference and spend the night there in the midst of people without any problem (Gladys: Incontinence status- dry)

Before now, I don't even know when the urine is pouring out but now if I lie down, I will feel like urinating and can get out of bed to go and urinate and come back (Fatima: Incontinence status- mild leak).

The return of continence control was related by Patience as “honestly...I have now returned to be a complete woman again”. The feelings of loss of worth as a woman that the incontinence conferred on her was replaced by feeling of a ‘restored woman’ upon gaining a dry status.

Post Repairs Physical and health Challenges

- Persisting incontinence issues

Persisting incontinence despite several repair attempts was a cause of psychological distress to women. When going in for repair, hopes are high that the leak would end, but this did not happen in every case. Christy lamented “at that time... I was just crying... some people they just do one operation and are cured, why is my case different”. Each failed attempt was a hope of recovery dashed at that point in time, nevertheless each woman remained hopeful for cure:

Sometimes I will burst out crying even as I sit alone because I keep thinking of how I can get myself free of this urine leakage and get back my former body. That is my fear...If people see me, they say I am losing weight, I am just thinking...it's not that I lack food...I don't have...I have enough food to eat... I pray that this urine leakage will cease...Leaking is still a problem; I want to be free of rags and walk around like normal people and be rid of rags... (Nanchit)

Honestly! There was a surgery I had that I couldn't forget. I had the catheter on, when they removed the catheter and I saw urine coming out, I went to the gate and sat down, there is a well near the gate. Because of how bad I was feeling at that time, I began to think of throwing myself into the well, so they will look for me and not find me. Here was I sitting close to the well... Anytime you have the surgery, you come out with the hope that that will be the end of it but up to now, I am still hopeful that by God's grace, I will be healed (Halima)

The numerous journeys, separation from family to seek cure and the financial drain led to debts, which contributed to strain on family relationships. Consequently, the display of fatigue by family towards continued provision of support to seek care was exhibited. Women narrated how family members' properties like farm lands, houses, and livestock were sold, and loans taken all towards supporting the search for cure. In addition, over time when cure was delayed, they observed that relatives exhibited reluctance in providing further financial support. Talatu lamented “when this sickness came, and I stayed for a long time without getting healed... many of them pulled back”. Women

expressed feeling of frustration over family members' attitude towards their continued determination to seek cure change. Halima narrated about her in laws fact finding visit to the repair centre to verify her true condition and her husband's recourse for her to accept her situation. Rose on her part, decided not to continue to be burden on the family, by moving on alone to continue to seek a cure. Hence despite the sign of support fatigue by family, women were undeterred expressing their unwavering commitment to keep seeking for a cure, exhibiting resilience in their determination:

I have gone through the problem of leaking urine for the past 22 years. I have suffered it... When the going got tough, I just told my parents to rest, I will come alone. My mother asked me, "You are going alone". I assured her I will go alone, there is no problem. That is why you are seeing me here all alone (Rose)

Even during my last admission, my husband's relations sent some people to come and investigate if I am really here and whether I have truly had the operation, or I am just sitting down here...left for him (husband), I should accept my fate and live with the urine leakage... but, how can I? I want to live a normal life and be free of this urine and I remain hopeful one day I will be rid of it by God's grace... (Halima)

VVF brought me into conflict with my family and now in my family, there were disagreements among them and they stopped seeing 'eye to eye' with each other. Up till today, my father does mention this to me. He is not coming out to ask me to pay the money he claimed was lent to assist me, but from all indications, he hasn't given up on me paying... (Sarah)

- Sexual and Reproductive health

The difficulties in sexual relation and reproductive health highlighted by the women after fistula development did not appear to have been alleviated by the repair. Some women still observed leakages and penetration difficulties during sexual intercourse, which hindered sexual relations. Additionally, some women observed changes to their menstrual flow:

We were having sex...but sometimes he will be complaining that I am denying him access to my body he feels he cannot penetrate when we are having sex...but I use to tell him that I have had surgeries which I have no control over, I had a surgery...if there is any problem, I don't know about that (Alheri)

... My menstruation has changed... it does not flow as before, and it comes with serious pains in my abdomen...(Christy)

Women and their spouses were unhappy and uncomfortable with these developments. Two women described how they remedied sexual difficulties by seeking assistance at the centre. Sarah received counselling on how to address the leakage during sexual intercourse, while Halima had a corrective surgical procedure. On the other hand, Alheri reiterated how her partner's willingness to communicate and cooperate could have facilitated receiving assistance from the centre in resolving the sexual difficulties:

...as for the urine leakage...When I came here, I gave them this complain and one of the things I was told during my treatment was that I should go and urinate before sexual intercourse, whether I feel like urinating or not. If I am able to do that, we will not have any problem (Sarah)

...Well I once faced a problem after the first surgery I had. They closed the place so there was no menstruation, no sexual intercourse but when I came to this place, I met Dr KM and after one surgery, that problem was solved... (Halima)

Since things turned out that way, if only we have had time to talk amicably, if he has come out to tell me what he had in mind, I could have called you here to say... this is the problem I have with my husband so I can come and have a surgery that will open me up. But he didn't come out to tell me... If that was the problem, we could have talked... maybe even arrange for him to help me with transport... (Alheri)

Significant fears of future fertility problems were expressed, and the inability to conceive were perceived to contribute to continued stigma related reactions from family or community members. This was more pronounced among the still married with partners in polygamous relationships. In these instances, mockery was rife over women's

childless state, hence creating more marital strains and tensions. Therefore, triggering feelings of frustrations and personal vulnerability:

Truly I am very worried as a result of lack of children. Barrenness is not a small 'disease' to women because you will also want to see your own even if it is only one, it is now 22 years I have not given birth again. I have had miscarriages about five times, but each pregnancy has never passed three months... These are the problems I am facing... Someone told me she (co-wife) is the one telling everyone of my condition. She has four children and I don't have even one...Honestly, this issue is hurting me seriously... (Halima)

My condition, worsened by my childlessness is what I believe is the cause of all the troubles I am facing in my home. I have become an object of ridicule... I am being mocked every day to the extent that my husband has now taken a second wife...I do not have a say in my home anymore and it is really a painful thing to me...my husband makes it a point of duty to remind me of my lack of worth... the insults I face is just too much that I will not want anyone to pass through the same... (Sarah)

On the other hand, three women Patricia, Nanchit and Maimuna had children post fistula repair. Patricia despite her initial fears on fertility or fistula recurring was able to have children. Nanchit on her part had two more after she started accessing care. Women narrated their experiences:

It did not affect our sexual relation...since I even had three pregnancies with him though I am still leaking... (Maimuna)

... I was thinking I might not be able to have children or the fistula might reoccur. But my menstruation was coming out normally... About three years after, I became pregnant; this child (held a baby) is my second baby after the VVF surgery (Patience)

- Post Repair Complications

Some women described having post repair health challenges that required additional surgical procedures or medical attention. Thus, contributing to prolonged poor health and incapacitation; hence the ability to resume life after treatment was further jeopardised. Maimuna and Fatima both had bladder stones removed surgically. Bladders stones are known post-surgical complications; hence surgery is at no financial cost to patients. The impact of the health challenges on their continence status was of significance concern to women. For Fatima, the procedure led to improved continence, while Maimuna observed her leakage appeared to worsen after each procedure:

I had lower abdominal pain, abdominal pains... and for two years I was unable to come back... I came and saw the doctor...The doctor told me that the pain was caused by stones and ...I had the surgery and the stones were removed...when I finally realised I was healed even though not completely was after the removal of the stones. I kept asking myself how I am now able to feel well...that I can sit down without using rags...that I can walk around without putting on rags (Fatima)

I started having lower abdominal pains, so I came back here, and they said they were going to clean my bladder, which they did. Anytime they did the bladder washing and I get back home, the pain will be even more severe than it was before my coming here, sometimes it will even shut down the bladder to the extent that sometimes urine will not come out again and at other times, the urine will be pouring out. That was how I kept going home and coming back to the hospital... That is how it is up to date (Maimuna)

In another dimension, Damaris had additional surgeries for loosened stitches and repair for hernia, and Halima at the time of the interview had been diagnosed to have a hernia. Damaris' experience of post-surgical complication was another source of emotional stress due to her inability to pay for the procedure and the leak that resumed immediately after the procedure; all of which were eventually resolved. For each woman, the question and fear, was of 'what impact this is going to have on my current continence level' and whether it would worsen it. Happily, for Damaris, her dry status was restored after the last surgical procedure:

Our road is not good and as I got home, the inner stitches got loosed, after about three months at home, I noticed that my stomach is getting bigger, so I came back. I had the surgery for the stitches and there was no problem. When I got home, I noticed something like menstruation, but it was coming from the anus and the swelling. I became very disturbed, so I came and complain to them here ...after surgery was done and the rubber (catheter) was removed... I was soaked in urine...so they placed the rubber back...I became devastated and worried, what has happened again, could it be the urine leak has come back?... I had to be taken back to the theatre...And when finally, the rubber (catheter) they put in was removed, the leak had stopped...I was so relieved... I am grateful to God that the leak has gone (Damaris)

- Recurring Fistula

The cases of repaired fistula breakdown were reported. To avoid such incidences, counselling is provided upon discharge on the importance of allowing their bodies to recover fully. This advice included, avoiding strenuous actions, delaying sexual relations until after 6 months and also the importance of returning to the hospital for subsequent deliveries. Nonetheless despite the counselling, Gladys and Maimuna experienced the breakdown of the repaired fistula. Gladys was due to exertion and Maimuna's inability to pay for a C-Section for a post repair pregnancy led to a worsened leak after a vaginal delivery:

But when I saw that I was getting better, I escorted my sister to the farm one day. She gathered some firewood and asked me to help her lift it. As I put my energy in lifting the firewood, I heard a sound...paaaaow!!! My stitches coming apart! I said "wonderful"!! And that was how the leaking returned (Gladys)

When I got home, I became pregnant... I came here and did scanning and was to come back and deliver here but I couldn't raise the money to come for the C/S so I delivered at home... After delivery, the leakage increased...it had in fact reduced significantly...but now the leakage increased (Maimuna)

5.5.2 Other Treatment Attempts

Traditional Healers

When the women were seeking for a cure, some did not limit this to orthodox medicine. Women narrated seeking care from traditional healers. Some of the women attributed their opting for traditional care was because of financial difficulties in their desperate search for a cure. Women narrated their encounter with traditional healers were all fruitless care seeking experiences. Gladys narrated her experience:

... my brother had taken me to one herbalist in Doma but I didn't get any better...there I was with it...no cure, till 2007...They gave me some leaves...different leaves... and asked me to be bathing with it, there is a powder that resembled saw-dust and instructed that after bathing with those leaves, I should put the saw-dust like powder into a clay pot and light a fire on it and inhale...I was on that for close to one year without any improvement (Gladys)

I suffered many things from traditional healers, all with no results. Can you imagine I had to eat a whole cooked chicken with the feathers with just the arms cut with some concoctions in it? I even had to eat a whole head of a sheep with the hairs on it also cooked with some concoctions. ... Even the one that you use smoke, you burn some herbs and cover yourself up to inhale the smoke...all these I did...All with no solution, I was still leaking... (Rose)

Over the Counter Medicine

Two women related using over the counter (OTC) medications purchased from a chemist during their quest for a cure. Asmau used the OTC medicines specifically to cure the leak, while Maimuna used hers to treat the foot drop she had developed as a result of the fistula. Both women related their experiences:

I went to one chemist where a woman asks me to undress. She put her hand in my private part and told me that there are medicines that can stop the leakage, so she put some medicines together... I took all those medicines, but nothing happened...so I said ok...I just decided to continue living with it... (Asmau)

I have taken both native and modern medicine because of the leg. It took me a long time to be able to stand up, so they were bringing both native and traditional medicine. My father didn't like native medicine, so he was the one bringing the modern medicine. My mother was the one bringing the native medicine and I was mixing the two... (Maimuna)

5.5.3 Support Network in Treatment Process

a. Informal Support Network

The family and fistula survivors played significant roles in the treatment process. The family was instrumental in getting women to the repair centre for treatment; by facilitating the transport cost and serving as the secondary care givers while women were receiving treatment. On another hand, fistula survivors in addition to providing information on repair centres, in some cases served as escorts in locating the centre. Significantly for all women, the sighting of other women on arrival at the repair centre helped them to allay their fears, and had psychological healing effect:

I was there with the urine for three years... Later we heard about Jos through a woman that had been treated here...the woman heard about me and came to look for me...so I told my elder brother that there is news, this time it is about Jos and I cannot keep sitting down with this sickness (problem). My brother looked for money again and gave me, it is that money I used to come to Jos with the woman that told me about this place (Alheri)

...When I got here I was relieved when I saw other women in the same condition, my real fears came down. I stopped being ashamed, even if I was wet, I started feeling at peace with myself, I stopped thinking like I used to in the pasts, on seeing all the women like me. My fears all left, I felt relieved... (Margaret)

The development of strong kinship was demonstrated by the friendship formed on the realisation that they shared something in common, and therefore could live freely without the fear of stigmatization from anyone. Forthwith, women became at ease and the feeling of shame and apprehension were replaced with acceptance and hope of recovery; hence setting the women on the journey to recovery. For women with

persisting incontinence issues after repair, this meant prolonged hospital stay among kinsmen and development of long term friendship.

...Honestly, I am no longer friends with friends that are healthy, honestly, I will not hide it from you...my friends...all my friends are those with leaking urine... people with my sickness. Why, because when I go among them I am not comfortable... while others because you have this sickness will stigmatize you... you touch even a plate, you will notice they do not want to touch that plate to use it...so that is why I stopped being friends with my healthy friends like I used to when I was healthy and my friends are those that are like me in the same condition. We relate together, and I visit them, they visit me, most especially though that we are always together in the hospital. As you would have noticed how we relate with one another here... (Halima)

Usually in most cases, family members served as care givers while on admission as earlier stated. However, another significant role peers played at repair centres was to assist in providing care for women that lack family members to provide care while on admission. Women will usually step into the care giving role naturally providing every necessary support, the group identity playing a prominent unifying role. Halima narrated the processes involved in the 'group' caring role:

...Among us...among ourselves... those of us in the 'leaking urine group' normally assist one another. If you have been given a long time to wait for your repair, you will help to care for those on the bed. And this one, if you are better you help to care for another...that is how we do it helping one another and that is how it was with me (Halima)

...That woman started nursing me... I never knew the woman before, but we spent two days with that woman helping to care for me before my aunt from Bukuru came (Loveth)

b. Evangel Vesico Vaginal Fistula (EVVF) Centre's Support for Treatment

The centre provides rehabilitation services through its chaplaincy; this includes, physical, psychological and spiritual support; primarily counselling on professional or spiritual

level. The physical supports were: literacy classes, free skills acquisition program and freedom ceremony. Every woman receives the psychological counselling upon admission and throughout the treatment, however participation in the literacy and skills acquisition program is voluntary; women are introduced to the services and encouraged to participate. The spiritual counselling was provided on the 'need for' it basis.

The participants in the research were all women that had gone voluntarily through the various rehabilitation services. The narratives provided insights into their rehabilitation experiences. Each woman joined the rehabilitation at different point in time of her treatment; this was either after repair upon discharge, or while awaiting subsequent repair. All the women had different period of training ranging from three months to one year. The choice of what skills to learn was based on self-choice of available options at the time of enrolment, the two most common were knitting and sewing, and other seasonal skills provided, were soap and pomade making classes, pastry making and beads. They narrated their experiences:

When I came, I told the people here that I want to join the rehabilitation centre. I was asked to go ahead. So, I joined, and we were being taught there was no problem... they were teaching us... Knitting, I went through the whole training for one year and was discharged (Asmau)

It was fun, there was cordial relationship among the people both trainers and trainees. They started teaching us using the wall, when we got used to it, they moved us to using pieces of rags, how to measure, how to cut, how to sew.... I learned plus pancakes which I still do...I was there for three months (Nanchit)

Benefits of Rehabilitation Program

Women paid glowing tributes to the centre for the opportunity to learn a trade free of charge. Table 5.5 below provides a summary of the benefits gained from the rehabilitation program.

Table 5.5: Benefits of rehabilitation

Type of benefits	Quotes
<p>Physical</p> <p>Seed support for business</p> <p>Less strenuous occupation</p> <p>Skills acquired at no cost</p>	<p><i>Those items that were given to us...the wool, the tape... were what encouraged us to get into the business, which I am still doing (Loveth)</i></p> <p><i>...Everyone in our house is into steaming and milling rice which is a very difficult job that I cannot do now, so I say thank you to God... that God has blessed me with something easier in this sewing....so even if I am in pains, I can still sit down and do my sewing...(Maimuna)</i></p> <p><i>Yes, it is very helpful because we did all the training free and we were fed in the place and after the training, what we learned is now helping us (Talatu)</i></p>
<p>Social</p> <p>Self-isolation stopped, improved interaction and socialising</p>	<p><i>Even though I did not have a sewing machine when I returned home, because I had learnt the trade here, I was able to start going out to my brother's shop that had a sewing machine and I started interacting with people... It helped me to go out of the house (Damaris)</i></p> <p><i>Even though I am not using it, I can say it has helped me to come out and be myself again... I was not going anyway when I had the challenge... not even church, but now I can go anywhere I want without fear. I am now out of my village and I am even helping to sell food in a crowded car park... I meet different kind of people every day... me that was hiding inside a room from people (Christy)</i></p>
<p>Economic</p> <p>financial empowerment, self-sufficiency & autonomy</p>	<p><i>It has helped me a lot in areas of the things I have learned because if not for this, I have no other means of livelihood. I am sewing in addition, now I sell wrappers and small dresses. All these have been of great help to me...(Fatima)</i></p> <p><i>It has also helped to increase my sources of income.... I can get some little money to spend (Nanchit)</i></p>

	<p><i>I have become a trainer that has trained others who are now good at it and they do it and sell to make a living. And I am making something that I can use to buy detergent to wash my things, buy other things out of it. I am no longer depending on my husband, if he is able to provide, fine; if not, I use what I was able to make(Halima)</i></p>
<p>Psychological</p> <p>Improved cognitive ability, mental capability, improved self confidence</p>	<p><i>I looked at myself and couldn't believe the change that has taken place in me...that I can even make money after losing all hope and pitying myself... So, I can do something useful...this really encouraged and strengthened me. This I think, is one of the contributions that made me to even go and further my education in college of health (Patience)</i></p> <p><i>The rehab helped me to see I could learn things... it provided me the opportunity to do something useful with my life. Because of my learning experience with the literacy class, like I told you I have gone back to continue my secondary education (Margaret)</i></p> <p><i>It opened my eyes... I saw that there is something inside my brain too and I have the ability to do things. Initially, I was afraid, I never believe I could do anything... I thought it was only people that went to school that had such abilities...I was crying, I didn't want to do it initially... I was afraid, but the counsellors encouraged me and told me I could do it if I tried. With the crying...I now started... I kept trying and trying...finally I was able to make it (Alheri)</i></p>

Challenges Faced by Women During and after Rehabilitation

In-training Challenges

The majority of the women did not have complaints concerning their training experience, however one participant, had issues of concern. It was observed that the majority were women that had their training over four years ago. While the lone complaint came from a most recent graduate (2 years), Talatu complained about a shortfall of teaching materials and inept trainers. Hence, she attributes this, as the

reason why she was not well skilled in sewing. Visits to the centre during the period of data collection, confirmed the issues raised (trainers sleeping on duty, trainees teaching each other). This observation was presented to the director of the centre, who confirmed the allegations and reported that lack of funds for rehabilitation had slowed plans to totally revamp the rehabilitation program. He further stated that sponsors were willing to provide funds for surgical repairs rather than rehabilitation programs. Talatu's comments:

...Ideally, if a person is learning under you, you are supposed to take your time and show him how and what to do carefully and sometimes if you give them something, they will be behaving lazily. Some of them will even get a place and sleep at work. We were not happy with that because we are supposed to have taken something home that will show that we have been to a training centre... We had to look for the designs... sometimes we will go around tailor's shop from here up to Apata looking for pieces that we will bring to work with. Honestly, that was what happened at that period of time... (Talatu)

Post Training Challenges

The major challenges reported by other women in the narratives, were those faced on return to the community after the completion of the rehabilitation program. Women complained of inability to locally source raw materials and high cost of raw material, which made their finished product unaffordable. Others were lack of capital to start off - some could not afford the equipment (sewing or knitting machines), thus could not put their skills to use. Again, community members were not conversant with some of the products, namely -liquid soaps. Lingering post repair health challenges also limited the use of acquired skills and length training was not adequate for some women to acquire enough skills to be economically viable

The people in our village have not understood the soap well but when I prepare the pomade, people buy, and it finishes quickly. The problem is getting the ingredients needed to make the pomade is difficult in our area (Alheri)

Due to lack of money...I was not able to buy a sewing machine. And I did not learn for too long (Rose)

... Because of so much up and down, I have not been able to buy sewing machine... I have not really worked with what I learnt...when I am fully recovered I hope to buy a sewing machine when I get back (Damaris)

Coping with Long Term incontinence

To restore some form of normalcy to daily living that had been disrupted by incontinence, women with persisting incontinence despite several repair attempts devised physical techniques to manage the incontinence. Two women that had over 15 years of living with fistula described this and the strategy was warranted to avoid the associated difficulties of rag use. Halima and Loveth described their two different strategies in coping with long term incontinence:

Because the thing had lingered for too long, definitely you must know how to take care of it since you have had it for years, it is not for one year or two or ten but many years... it is with you always. So definitely I have to find a way... you know it is not like menstruation that will flow for a while, this is something that flows none stop so you have to know how to manage it especially since you don't have the resources to be buying things like pampers and even if you have the money, doing this on daily basis will run you down, 22 years is not a joke. I got an idea of going to the second-hand clothes dealers to buy towel that I will bring home and cut to pieces that I will be using as I wash them...but since I learned how to clean up and use them properly, I have since forgotten the last time I saw a rash on my body... (Halima)

I encourage people to get use to their system so as to be able to know when they need to go and urinate. They need to discipline themselves to squeeze themselves in so as to keep the urine from dripping.... when you keep holding yourself, after some time you will feel the urge to urinate...then you will go and squat and release the urine...You have to keep disciplining yourself to be able to do it...it will become a part of you... (Loveth)

Two women described the masking of associated smell with the use of perfume only (Alheri and Talatu) and that was after reintegration. Women that used perfume appeared not to have had the capacity to afford this earlier.

I started buying just recently, before now, I did not have the money to buy perfumes during those time (Talatu)

5.6 Returning to Life

5.6.1 Defining 'Returning to Life'

The return to life will also be referred to as reintegration; is the process of returning to normal living after fistula treatment (surgical and non-surgical). Margaret, who had one repair and became dry in explaining her experience of recovery and returning to life related "...I took a long journey, now I am back into new life..." For women that had just one repair and became dry, to those that took several returns for repairs to achieve dryness and even those still seeking a cure, all appears to still be in an on-going reintegration process. In these women's narratives the experience of returning to life after treatment varied as each woman's journey to recovery is a different process and at a different stage, which is significantly linked to their current continence status. In describing her reintegration experience, Nanchit asserted "I feel good with life...my joy would have been greater if I was totally cured"

From the narratives, it appears that reintegration is linked to the impact of the consequences of fistula formation on them as individuals. Additionally, of critical importance to reintegration was the ability of the treatment and support received to mitigate the impact of fistula. For instance, Maimuna (with severe leakage) related about her reintegration "...my joy cannot be quantified as that is what I am enjoying now...the sewing skill". Suggesting the acquired skill made going home something to look forward to, for it provided more or less an outlet of the hidden frustration of delayed recovery. Halima, one of the two women in the study with persisting severe leakage, corroborated the frustration of home going by her expression of her continuing feelings of vulnerability due to stigmatisation faced:

“My hope each time I am returning home ...I am healed and that those that were stigmatizing me...will receive me with open arms” ... (Halima).

From the foregoing, the reintegration experience can be facilitated or hindered by various factors. This will be discussed in the sections below.

5.6.2 Facilitators of Reintegration

The level of support received determined the ability to resume life. These supports would be referred to as facilitators, which were contributory to reintegration process.

Psychosocial Support

It is important to reiterate here again that the physical, social, psychological and economic benefits of the rehabilitation program (see table 5.5 above), women believed contributed to the transformation in their lives upon return. Women mostly agreed that they were now placed on a higher pedestal in the family and community than they were prior to the fistula development. As Asmau claimed, “before that time, nobody knew me but now I am well known...” As side from Rose, who remained unemployed due to lack of capital and family support to commence business, all the other women were either involved in small businesses or returned to farming for sustenance; for women who did not have the support to utilise the skills acquired (see table 5.1, p.164). The dependence on family or neighbours for survival was stopped for many as described by Talatu and Fatima:

Things have changed because I have gotten something (sewing) that is helping me... when I was having the problem, they were the ones feeding me but now, I am the one fending for myself and I am still getting something (Talatu)

Honestly...the present life is better because now I am well, I have an income generating activity and I have a husband...Yes, now I have enough money to do things for myself and even to travel here without having to ask anybody for assistance... Now everything is going on well (Fatima)

Evangel Vesico-Vaginal Fistula Centre Valedictory Programs After Treatment

In the narratives women elaborated on activities organised by the EVVF centre to mark the beginning of their transition home. These are the weekly freedom ceremony and the annual reunion program. Every Tuesday morning, the chaplain carries out the freedom ceremony to celebrate recovery and prepare women for the return journey back home. Referred to as 'bikin salama' translated literally to mean 'farewell celebration' for women that have had a successful closure; women might have achieved dry status or still leaking. Activities during the ceremony include, a time of singing, dancing, and sharing stories of their recovery experiences. It was also a time of final words of counsel and advice from the counsellors and presentation of gifts for women that went through the rehabilitation program. Women reported that this ceremony was helpful to them in carrying on after returning home:

Honestly, I was very happy with my life because in addition to my learning, we were given some items at our discharge all for free. Like me, I learned knitting so when I was leaving I was given things like pins, wool, and needles for free. (Patience)

...It wasn't only the gifts, we were given some life skills to help us for post VVF living; we should not do anything strenuous for 3 months and after 6 months can one have sex with their husbands... I listened to them very well and they were very helpful... (Damaris)

Ha! Graduation ceremony after our training was what gave me strength when I went back. Those items that were given to us...the wool, the tape... were what encouraged us to get into the business, which I am still doing (Loveth)

The other valedictory event is during the annual reunion program for fistula survivors that were treated at the centre. This is an event that takes place every second week of March for the purpose of interaction with themselves and the wider community. Hundreds of women gathered for the three-day event. For women fortunate to have the valedictory ceremony to coincide with the annual reunion program of the centre, they are presented to the crowd of invited guests and fistula survivors. To be openly

acknowledged among dignitaries and peers was a thing of joy and pride and turning point for women that had been subjected to shame and ridicule. Women narrated the significance of this ceremony their experience:

I was very happy seeing the kind of free gifts that were lined up for us and as I heard them calling our names. I was very excited when my gifts were handed over to me. I got something I never dreamt of... (Patience)

The people that were responsible for training us, the invited guests and the dignitaries all came together in a celebration mood without stigmatizing us (Halima)

I was very happy...They cooked some special food for us, the things we did were displayed in the hall and...we were given things like containers, scissors, threads, needles, measuring tapes, yards and wrappers (Nanchit)

Family And/Community Support

The choice of where to return to upon discharge depended on their living circumstances before seeking treatment. This was influenced by who supported them while living with fistula and while seeking treatment. Upon discharge women mostly returned to the home they lived in while living with fistula, which could be the natal or matrimonial home. Women described the warm welcome received particularly when the status was now dry. In the accounts of women with numerous repairs, family members expressed unbelief as well relief on return home. Christy, who became dry after her seventh repair, described her mother's reaction of unbelief at her arrival: "she didn't believe me; she said I should undress myself, so she can see".

Women mostly attested to family members' support in adjusting to life. Family members assisted by helping with house chores for them to receive the required rest necessary for recuperation. Some mentioned family supported them by assisting in the purchase of equipment to start off business with the skills acquired. Gladys in her narrative described how her family supported her to further her education on return home, they were afraid the motion of sewing could cause her fistula to recur.

When I got back home...for two months, there was a girl that do stuff like cooking, sweeping and the rest for me (Nanchit)

...when I went back she (mother) gave me money to add to my own and buy that sewing machine (Fatima)

I assembled my sewing machine and was sewing stuff and making money and was meeting my own needs, but they said if I sit on the sewing machine it will affect me, so they bought a form for me to go back to school (Gladys)

Community support appeared to be mainly in form of welcome receptions, which were organised to celebrate return home.

...there was nothing that the village as a whole did for me...My women church group welcomed me by presenting me with a new uniform... if you see the crowd that gathered the day they presented the uniform to me; it was like a celebration... (Damaris)

...When they heard that I am back, they came with their musical instruments and danced in celebration with me. They gave me some money to buy soap with (Patience)

When I arrived with that knitting machine people gathered in the house both adults and children, everybody was very happy saying I also came with a machine!! Oh!!...they came with little children shouting, "Mama P, has come" ... they were happy that I came even with a machine! Oh! (Asmau)

In comparison to family support, community support in terms of providing physical assistance appeared to be minimal. Two women, Asmau and Gladys however in their narration described the support community members provided on return home

They knew I was back... but they have never helped me, it was only me and my brother... I was going everywhere before... but after I got this problem... everyone left me except my brother (Alheri)

I was not able to farm that year so whenever I have need, people will gather foodstuff for me (Asmau)

Now I attend church services, I am in the choir, I even attend youth programs, and the youth group themselves, went and helped me in the farm (Gladys)

Additionally, two women Asmau and Patricia took a step of publicly declaring their recovery on return home. Asmau narrated about going into Church to give special thanks for her cure and the sewing machine gift she had received. Patricia equally had a special church thanksgiving organised to celebrate her cure on her return home.

I took the machine to church where it was dedicated, and I told everyone to help me give thanks and people responded...I was happy!... The next week, I used the wool I was given here to knit something that I took to church as my thanksgiving offering (Asmau)

I even had a thanksgiving in our church thanking God for what I had gone through and how God healed me (Patricia)

Resolution of Stigma

Another facilitator of reintegration was being accepted and allowed to function without experiencing the acts of stigmatisation. This meant for Gladys, the acceptance as 'any ordinary human being' allowed to live a life free of stigmatisation. Loveth had faced severe stigmatisation from family, the change in her economic status translated into a change in their negative attitude.

VVF has cheated me, people have rejected me to the extent that even to fetch a cup of water.... and drink inside our house became a problem! I never knew that I will become like any ordinary human being, but I thank God, I am now better (Gladys)

...'kai'! Things were different when I returned home... there were real changes...not like it was in the past... (Loveth)

5.6.3 Barriers to Reintegration

Long recovery period and/stigmatisation issues

Women with post repair physical and health challenges as earlier discussed (section 5.5.1 above, p. 203) described this as an obstacle to reintegration. It is pertinent to reiterate here that women were of the view that their lingering physical and health challenge that required numerous journeys back and forth the centre affected their reintegration. Hence, they had not been able to settle back and put to effective use skills acquired during their rehabilitation program that would have facilitated their reintegration (see section 5.5.3 above).

Additionally, not all women were willing to leave the centre after discharge from rehabilitation. These women had faced stigmatisation issues during the long period of seeking cure. Therefore, just like resolution of stigma after repair facilitated return to normal living for some, women that still experienced stigmatisation attributed this as a hindrance to resuming life; hence the continuing preference for stay at the centre. Halima and Loveth described this:

... At times, I even will even be thinking that it might have been better if I had remained in the hospital instead of coming back home because at times, staying in the hospital is more peaceful than staying at home. Because in this place, you come across many people with similar problem and there is no discrimination or stigmatization but at home, the moment you stand up, they will be looking at where you sat, the moment you turn your back, they will be looking at your back to see if the urine is running down your legs. None of that will happen here in the hospital even if you are the only one with it (Halima)

... Our going back home... 'Kai'!... was because they drove us away from here... not because we wanted to go back, really we did not want to leave this place. You needed to have been here to see how we were... we even had a women fellowship group here, we will sit down here and learn songs that we will go to church and

sing on Sundays...at that time...They had to tell us, they no longer wanted to see us here again by the next day. Before we started leaving for our homes (Loveth)

Related to this experience of acceptance, one of the reasons why Rose decided to leave her community after a point in time back on the long road to recovery was because of the side comments by community members about her lack of recovery. Rose moved to the city where the centre is, and this is where she calls home down the long road to recovery.

Fertility Issues Post Repairs

This is a post repair physical and health challenge, which in the narratives was observed to be a major obstacle to reintegration, hence it, is pertinent to discuss further on it. Whether dry or still leaking, women with fertility issues still face difficulties in family living that are of grave concern. Childlessness as earlier discussed, contributes to continuing tension within the family. Additionally, within the community, labelling (black listing) can be involved as was experienced by Alheri. Community members expected her not to have remarried because of her history of living with fistula, hence blamed her for the failed second marriage.

...now I am better, I am free...I am free when I am with friends and other people, however in my house up till now I am not very free. Living in freedom in my house is not possible since up to now, I am not getting the blessing of wedlock...the fruit of the womb... (Sarah)

VVF has affected me...as a woman... since I got this problem, I have never conceived again... I stayed with my (second) husband for one year and did not conceive... when I was planning to remarry, people in the neighbourhood started asking why I should marry knowing that I have a problem. Now that I am no longer with him, they were saying that at that time they had asked me why I wanted to marry knowing I have a leaking problem, saying my being sent out was the result of what I have done...(Alheri)

To mitigate the associated pressure of infertility, Fatima narrated encouraging her husband to marry a second wife; due to her inability to conceive post repair and her fear

of increased leakage with subsequent pregnancy. Despite recognising what threats the presence of second wife posed to her relationship; her decision might not be unconnected with societal view on childless marriages. The desire to safeguard her health from fistula recurring with the pressure to have a child of her own prompted Fatima's decision. This action was taken to reduce the pressure and safeguard the relationship with her husband.

He stayed with me for four years ...it will not be proper for him to stay without a child. I encouraged him to marry hoping that God will bless his marriage with a child and when he did, he got a baby girl who is about two years now... honestly there is no problem, we are living in peace (Fatima)

Unresolved Marital Conflicts

None of the estranged marital relationships upon fistula development were restored after women were cured. Women, who could not return home due to family estrangement, had different views about what the separation from their spouses meant to them with respect to resuming normal living after treatment. Women with children prior to development of fistula despite ill feelings about their partners' attitude still desired to return to their matrimonial homes but were forced to live elsewhere against their wishes.

I wasn't happy because I wanted to go back to his house but instead I had to go back to my parents' house. I wasn't happy (Tlatu)

I built a small structure that I and my children are living in, not that I have rejected him, not that I have married again...I am there living for him...waiting (Asmau)

On the other hand, women without children appeared unwilling to return to their matrimonial homes and were content to start life again elsewhere. Margaret and Damaris' partners attempted to make reconciliations after they were cured but backed by their families were unwilling to return to their matrimonial homes. The two women, Margaret and Damaris narrated how their spouses attempted to restore the relationship:

He came back after I was cured and discharged from the hospital, but my father asked him to leave. He told him, "Why have you come to see us, is it because she is cured now? if she had died is it her dead body you want to come and see in this house, what are you looking for here, do you want to destroy her again, is it because she is now healed, you do not have a "girl" again If I ever see you again, I will call the police" (Margaret)

He said I should come back...but I said I will never go back... My mother said she has never seen such an attitude and now that I am healed, he now knows I am his wife? ...she will not allow me to go back to his house (Damaris)

For women unwilling to return to their matrimonial homes, returning to life meant staying in a place of acceptance. A major concern was the fear of fistula recurring again, which they considered a hindrance to future relationships.

5.8 Conclusion to Chapter

This chapter has presented the results of the analysis of women's narratives on their experiences on living with fistula. An abstract of a participant's core story was presented to give an overview of a typical story, and the collective experiences of women were presented in a chronological order along three plotlines fistula ordeal, treatment process and returning to life. The next chapter is set up to provide the discussion on the findings with respect to findings in literature. The discussion will also highlight the linkages of the findings of the research to theoretical concepts. Finally, it will highlight areas of contribution to the body of knowledge, the implications for interventions, policy, and the need for future research.

CHAPTER SIX

DISCUSSION

6.0 Introduction to Chapter

This chapter provides the discussion of the findings to answer the research question:

How do women attending a reintegration service describe their experience of living with fistula?

The chapter is structured into two sections. The first section evaluates the findings along existing literature, this includes studies that were published and identified after the literature review that informed how this study was conducted. The findings are presented under the headings of the plots: fistula experiences, treatment process, and returning to life experiences. The second section presents the theoretical concepts that provide an understanding of the meaning of phenomenon that impact upon the experiences of living with fistula. As earlier discussed in the methodology, these first two sections are based on the 'process theory' by Pentland (1999); the antecedent and consequences approach of the building theory process requires looking for associations in the conditions that triggered the process and in the outcomes of the process (Pentland, 1999).

6.1 Part A

Women's whole experiences of living with fistula, included the history, social structures, cultures and beliefs within which they are situated and that which became situated inside them/ the meanings which the experiences produced in them (Williams, 1984, Klienman and Seeman, 2000). In discussion about the different experiences, consideration is given to the changing political, historical and physiological realities in which the experiences are situated (Klienman and Seeman, 2000).

6.1.1 Fistula Experiences – Fistula Formation

Obstructed and prolonged labour as described in all the narratives led to the development of obstetric fistula. The focal actors in the narratives, who were also the narrators, were fistula survivors. In the narratives women appeared to be passive

participants in the birthing experiences that culminated in fistula formation. The prevailing circumstances during the birthing process that led to fistula were clearly controlled by various influencing factors fitting into the Thaddeus and Maine (1994) 3 delay framework. The influence of 'others' caused: the delay in taking a decision to seek care [delay one]; geographical location and inadequate transportation caused the delay to the health facility[delay two]; combined with a poor health care system caused the delay in receiving the appropriate care at the health facility [delay three] (Thaddeus and Maine, 1994).

The influence of 'others' in the narratives identified as family members, TBAs and SBAs that presided over the birthing process is suggestive of women's lack of self-autonomy to influence seeking health care; this caused the first two delays. Roush et al argued that the typical characteristics of women that develop obstetric fistula places in them in the position of gender power imbalance positions, which contributed to fistula formation (Roush et al., 2012). Women in this study were all from a low socioeconomic class and resided in rural locations in Northern Nigeria at the time of incidence. Prior studies show women are typically young, poor and of rural location, hence they lack the power to challenge norms and negotiate reproductive behaviour (Wall et al., 2004, Melah, 2007, Meyer et al., 2007, Ijaiya et al., 2010, Alio et al., 2011, Abrams, 2012, Barageine et al., 2014, Gebresilase, 2014, Hamed et al., 2017). Education, socio-economic status and location are strongly associated with utilisation of maternal health services. Women of low education with poor socio-economic status living in rural locations were least likely to have delivery assisted by SBAs in Nigeria (Babalola and Fatusi, 2009, NPC and ICF, 2014). The powerlessness of women to influence their birthing experience was clearly demonstrated in the study. This lack of autonomy can also be attributed to women's lack of financial capability, as the choice of home delivery for women was influenced by their lack of finances. Women did not have finances at their disposal to seek medical attention when the spouse could not provide money. However even for the few women who choose to go to the hospital, these were still powerless because of their geographical location and the poor health care system.

Early marriage in Northern Nigeria is reported to be one of the social factors contributory to the development of fistula with poverty as the underlying cause (Wall,

1998, Tebeu et al., 2012, Barageine et al., 2014, Hamed et al., 2017). Cultural norms particularly among the majority ethnic group the Hausa/Fulani in the north support the practice of early marriages, hence the resultant pregnancy before the pelvic region achieves full maturity (Wall et al., 2004). These aspects coupled with malnutrition results in entrapment of the foetal head in the mother's pelvis, caused obstructed labour (Kelly, 1992, Cook et al., 2004, de Bernis, 2007, Hamed et al., 2017). In Wall's (2012) analysing framework for fistula formation early marriage was the major route of entry. However, this was not the case in this study as only two women were aged 14 and 15 years at time of marriage, the others were aged 18 years (total of four were below twenty years) and above. It is pertinent to note that the two young women were the only ones that attributed the reason for preference for home delivery to cultural norms and for one of them; there was no clinic in the village. These two incidences occurred as at the time of data collection 22 years ago.

The higher than expected median age of first marriage among the participants might suggest the gradual impact of on-going campaigns to discourage early marriage and encourage the education of the females by the government of Nigeria in response to the MDG (WB, 2011). It is important to note here, that only one woman was from the Fulani ethnic group noted for early marriage custom. However, further research would be required to verify if there is a positive shift among the rural population with a larger sample size. Studies have argued that early marriage and cultural issues that limit women's autonomy are underlying reasons for fistula development (Wall et al., 2004, Melah, 2007, Alio et al., 2011, Gebresilase, 2014). However, in this study financial constraints were attributed to women who had TBAs attending as well as the women who had births assisted by 'SBA' at home. Furthermore, in this study, fistula formation occurred for nine women during the first delivery, while for six women it was between the second to fifth deliveries. Hence, women were from all the reproductive life stages and so concurred with earlier studies (Heller and Hannig, 2017, Degge et al., 2017). Authors therefore argued that since it happens to both younger and older women of any parity, lack of access to SBA and EmOC appears to be the primary cause (Bangser et al., 2011, Abrams, 2012, Phillips et al., 2016, Heller and Hannig, 2017).

A study by Philip et al (2016) comparing the causal narratives of health professionals and fistula survivors in Nigeria revealed while women attributed the cause to poor maternal health management and financial difficulties, the primary notion of culture and ignorance was held by health workers. Heller and Hannig (2017) asserted that more emphasis is placed on cultural factors, rather than the political and economic shortcomings, which were similarly observed in this study. Early marriage and preferences for home deliveries should not be overstated even though these are important cultural norms these are not the only issues. There is evidence from this study that other influences impact on fistula experiences, despite the small sample size. Even though there was a lack of access to EmOC due to location, financial constraints appear to be the first major reason for women opting for home delivery as noted earlier and is similarly reported by Philip et al (2016). According to the DHS, delivery in a health facility increases with wealth as the proportion of women delivering in a health facility increased from 6% for lower wealth quintile to 80% for highest wealth quintile (NPC and ICF, 2009). Studies similarly reported positive association of institutional delivery and SBA with financial status (Babalola and Fatusi, 2009, Ahmed et al., 2010).

Previous studies on fistula described preferences for home deliveries that were attended to by family or TBA. However, in this study interestingly there were cases of women who had a home delivery being attended and helped by an 'SBA'. Even though there was a paying arrangement, but the SBA's professional identity was unknown to the women; and this has not been previously reported. It is therefore important to investigate this new trend of home delivery assisted by the 'SBA' to examine any possible links with fistula development. The preference for home deliveries might not be unconnected with women trying to avoid health facilities, due to high user fee charges, awareness of poor medical practices, lack of health workers, and delay or refusal of services. Interestingly there were women in this study that sought immediate care at health facilities upon commencement of labour; but they also faced similar obstacles experienced by women who stayed home. The birthing experiences of these women, despite seeking care early, further exposed the inequitable access to maternal health care in Nigeria particularly in rural health facilities.

Research shows that structural inequalities exist in the health system of most countries where obstetric fistula is prevalent (Bangser, 2007, Wall, 2012a, Heller and Hannig, 2017). The influencers of fistula formation in this study clearly demonstrated this. A chaotic socioeconomic and political system prevails in societies where obstetric fistula occurs (Wall, 2012). This is referred to as 'structural violence'; as globally obstetric fistula is predominantly a disorder for poor women residing in poor countries (Abrams, 2010, Wall, 2012). The phrase "structural violence" is a way of describing social organisations that place individuals and populations in harm's way (Farmer et al., 2006). The organisations are *structural* because they are entrenched in the political and economic structure of our social world; they are *violent* because they inflict harm on people, and usually, those responsible for perpetuating such inequalities are spared of such harm (Farmer et al., 2006). Heller and Hannig (2017) argued that the focus on pathology of culture is a diversionary distraction from the structural violence that led to fistula formation and how women negotiate the pathway of recovery from fistula. The narratives in this study reflect the structural violence that contributes to the "differential risks" that led to fistula formation and resonates with the work of Klienman and Seeman (2003: 232). The failings of the society at the family, community and political levels and the perception of injustice highlights the structural violence. Abrams (2012: 43) described obstetric fistula as a 'disease' of poverty', and therefore a glaring indicator "of failure of the political, social and health systems to protect and promote women's health" and by extension, their rights to health. Therefore fistula formation is an indicator for inequities that subverts the capacity of girls and women to enjoy good quality of life after child birth (Bangser, 2007).

Interestingly, the foundation for the poor health system structure has been traced to colonization and post-colonization, and the Structural Adjustment Policies (SAP) that incapacitated local economies and public services (Kim et al., 2000, Potter, 2004, Heller and Hannig, 2017). The top down health system model in practice in the countries is a legacy of colonization; which emphasised curative rather than preventive care and the location of specialised care only in large cities. This laid the foundation for inequitable health access for rural and poverty stricken geographical areas (Potter, 2004, Scott-Emuakpor, 2010, Inem, 2014). The IMF conditionality's and SAP of the 1980s and 90s,

contributed to further weaken the health and education systems (Sparr, 1994, Leach, 2015). The conditionality led to reduced spending on health and led to neglect by government, which invariably contributed to the weakness in the health system (Leach, 2015). Hitherto, services in public hospitals were free or incurred minimal charges, but SAP led to introduction of user fees (Wang'ombe, 1995); which allegedly contributed to limiting health care access to the poor (Sparr, 1994, Peters et al., 2008, Leach, 2015, Heller and Hannig, 2017).

Additionally, the weakness in the health system in the affected countries should be considered to have been stimulated by the aid systems to fund projects on HIV/AIDs, TB and malaria (Leach, 2015; EP, 2015). On the international health scene, direct aid to health like the Millennium Development Goals are focused on disease or health issues such as HIV/AIDs, TB, malaria or maternal health (Kieny et al., 2014; Leach, 2015); in such scenario, health activities by government and Non-Governmental Organisations are vertical in operation and do not build capacity at ground level (Leach, 2015). Consequently, the overall support for the health system development is inadequate (Kieny, et al., 2014). The crises that exist in the health care system are reflected by the poor maternal health outcomes that have resulted in women developing fistula. Obstetric fistula has been used as a marker of the overall maternal health services of a country (Roush et al., 2012). Hence attention needs to be centred on addressing this inequitable access to maternal health in rural locations. Generating political will and commitment is suggested in redressing the chaos in the health system.

6.1.2 Fistula Experiences- Living with Fistula

The development of fistula led to series of life changing experiences that impacted upon every aspect of women's lives and relationships. The loss of control over urinal flow was both frightening as it was disturbing, as one of the women narrated it was an unacceptable return to 'bodily chaos of infancy' (Lupton, 2000: 58). The bodily changes caused by the uncontrollable flow of incontinence impacted upon body image. The body image is fundamental to how health, illness and health care are experienced and conceptualized (Lupton, 2000). Body image is situated within social, cultural and historical context; furthermore, it is responsive to daily actual experiences (Lupton,

2000). Hence the principal discourses prevalent with the socio-cultural setting an individual resides in, are crucial in determining how body image is constructed (Lupton, 2000). Chronic illness like obstetric fistula not only causes a rupture between the individual and the social body, in addition it makes the individual begin to reconstruct self on various levels (Charmaz, 2000) and reflects the divisions in socio-cultural dimensions highlighted in the narratives.

The incontinence triggered a change in identity perception. The different identities portrayed were signs of bodily awareness by women and attempts in reconstructing the malfunctioning and responses people provided. Identity attempts to link the self to the existing social structures. Identities are general and common facets of individuals that institute the 'what and where' women are within their social structures (Kelly and Field, 1996). Identity construction in response to illness is when personal identity and social processes come into conflict (Williams, 1984). Women through the process of mental dialogue drew upon past social experiences, cultural connotations and knowledge on the implications of current physical state and social existence in conceptualizing identity (Charmaz, 1983).

In this study the different negative identities observed were 'leaking' identity, group identity (masu yoyon fitsari- leakers of urine), and 'spoiled' identity. There appeared to be a form of temporality and a shift from one identity to the other. This fits with Yoshida (1993) explanation of identity reconstruction as being transitory, vacillating between identities. Beginning with the 'leaking' identity, then group identity on arrival at the repair centre, spoiled identity while still seeking a cure or after cure, and the improved identity (positive identity) manifested after treatment. These women's negative identities are a direct consequence of fistula formation. Spoiled identity refers to possession of attributes of stigma that qualifies an individual to be discredited; flawed or tainted within the stereotype of what a normal should be like (Goffman, 1963). Based on Goffman's (1963) definition of spoiled identity, all the negative identities could still be described as spoiled identities, however in this discourse; spoiled identity will be presented as a specific category of identity. In the narratives, these negative identities are as a result of the attributes conferred upon women as a result of fistula, as such they will be referred to as 'ruptured identities' (Riessman, 2015). The fistula formation caused

the 'rupture', and in the narrative reconstruction women attempts to repair the 'ruptures' between body, self and the world; wherein their identity no longer lies in who they are but in the incontinence now used to describe them (Williams, 1984, Riessman, 2015).

The leaking identity: The awareness of self and body was illustrated as described by Kelly and Field (1996). Women were aware of the distinction between who they were before now (self) and the new body (identity); living with the uncontrollable flow of urine/faeces that led to loss of place in the home and community; the loss of identity-woman/wife to being labelled as soiled (wetness and smell). Duties and responsibilities performed were no longer possible not only because of the ill health, but also largely due to issues around hygiene from the uncontrollable urine or faecal leakages.

Stigmatisation as a result of incontinence by spouses or friends or community members was noted. Movement was thus restricted due to these difficulties and led to the reconstruction of self; picking up the identity of the 'leaking woman'. These triggered feelings of worthlessness and personal vulnerability as women considered they were now 'reduced' women. The new undesirable identity changes also triggered the desire to seek a cure, signalling resilience. Making use of an illness idiom, the leak was viewed as a 'commodity' that was not 'purchased' therefore, it had an end date. Nevertheless, there was evidence of support and no woman described total stigmatisation as reported in other studies. Stigmatisation will be discussed in greater details in section below.

'Masu yoyon fitsari,' literally means the 'leakers of urine group'- this depicts a group identity. The name 'masu yoyon fitsari' is an identity of companions of the same fate, a far cry from the isolation felt before treatment, when women thought there was no one else with the condition except them. The replacement of bewilderment when contact is made with persons with a similar condition and the opportunity for self-comparison is afforded when dealing with chronic illnesses (Charmaz, 2000). The sympathetic others in the group all share the same stigma, and hence can instruct on how to get by, provide moral support and provide comfort (Taylor, 1991). As a result, this identity signalled the beginning of hope for recovery on arrival at treatment centre. Furthermore, group identity was a significant part of women's care experiences in the redefined identity.

The group referred to as 'sisterhood of suffering' by prior studies was similarly captured in the narratives (Wall, 2002, Wall et al., 2005b). For instance, Wall (2002) described the dance performance in the display of group identity as part of activities that takes place in the EVVF centre, which was significant in the rehabilitation process while receiving treatment. The 'sisterhood of suffering' explains the bond formed by women identifying with each other's plight. Wall (2002) asserted this experience as one of the most important facets of their treatment; he further described it as "holistic" medicine at its finest—surgical cure together with psychological support and kindred spirit (Wall, 2002, Wall et al., 2005b). This bond devoid of stigma and discrimination made continued stay at the centre a preferable option than returning home for women with persisting incontinence. Some women reported hearing about the availability of treatment centres from treated women. Additionally, when family support in providing care became strained, 'sisters' take up the responsibility to provide care and encouragement, this was similarly reported by Wall et al (2005) where fistula survivors provided what was described as the best unrivalled and empathetic nursing care in the world at Addis Ababa Fistula Hospital.

The spoiled identity reflects the physical (smell & wetness) challenges. Additionally, the underlying efficacy of this bodily dysfunction can be better understood within a deliberate account of the 'social process of womanhood' wherein lies a woman's purpose and perception of identity had become destroyed as was exemplified in the narratives (Williams, 1984:188). In the face of 'failings' as a woman as was evidenced in the narratives with respect to sexual and reproductive responsibilities within the prevailing sociocultural context; that could be termed 'double jeopardy' for fistula survivors. Generally the cultural representation of a woman's body is that of a reproducer, irrespective of her intention or capacity to fulfil the function (Shildrick, 1997). The sexual and reproductive health difficulties, contributed to family life disruptions for some women while living with fistula and even after treatment. Women sought to understand some of the restrictions conferred on them particularly with issues pertaining to sexual and fertility challenges. This is a crisis point as women sought ways to negotiate new/old relationships within a culture that defines woman's worth by her role as a wife and bound in the confines of successful motherhood. Those who were still

married faced difficulties in conception post fistula and became frustrated by their inability to conceive. Infertility and childlessness in an African context is viewed as a grave failing of womanhood and an accompanied consequence of stigma (van Balen and Bos, 2009). Children are highly valued for the sake of perpetuity, for it is unacceptable that lineage should die, instead birth of children is preferred (Makinwa-Adebusoye, 2001). Among the Hausas of northern Nigeria and most of the other ethnic groups, a woman's purpose is childbearing, and she is only considered to be a full adult woman upon successful delivery (Wall, 1998). Secondary infertility is one of the injuries in the 'obstructed labour injury complex' that fistula development causes. Scarification in the reproductive duct caused by the fistula hinders sexual activities and hampers future conception in most cases (Wall et al., 2005a).

There is a dichotomy in the response to the spoiled identity by the still married and single/separated women. While the still married were desirous of pregnancy and restored fertility, the single/ separated women on the contrary mostly desired nothing more to do with future relationships; due to the hurt experienced from rejections by their partners and the fear of fistula recurring with subsequent pregnancies. Pope et al (2011) noted similar responses by separated women in their study. This highlights the extent of the impact of the psychological trauma faced as a result of developing fistula; again, it also suggests the pressure for children exists mainly within a marital union which the single women are not exposed to, hence their reaction. Interestingly in other studies, married women with children were less likely to be divorced or separated because of fistula (Turan et al., 2007, Pope et al., 2011, Umoiyoho et al., 2011b), the contrary was observed in this study. Two women with children before fistula formation could still not return to their marital homes despite being cured. This could suggest that other factors might be responsible, for example spouses continuing to view them in the context of the spoilt body. Hence the spoilt body image was perpetuated despite their partners cure, and further research is required to explore and understand this anomaly.

6.1.3 Treatment Process

Access to care varied with some experiencing shorter periods of living with fistula, mostly within months (1-6 months) of developing the condition. The two older women

among the participants were the ones living the longest with the condition before receiving care. There is evidence of a growing awareness that the condition is curable as women sought treatment even though this took time to receive. This was outlined by a study in the centre in 2004 that showed a majority had lived with the condition for more than 12 months before receiving care (Wall et al., 2004). Similarly, other centres also report women presenting for treatment between 6 months to 12 months (Ekanem et al., 2010, Ahmed et al., 2013). There is also an increasing number of repairs being recorded at EVVF centre and other repair centres in Nigeria in recent years (Kirschner et al., 2010). Therefore, the shorter periods of living with fistula before repair experienced in this study can be attributed to the increasing awareness and availability of repair services in the country (Landry et al., 2013). This development suggests the backlog of cases requiring repair could gradually be cleared however this does not address why new cases are continuing to occur. Hence efforts around preventative measures must be intensified to guard against the development of fistula.

All the women except one had the support of family to access care at the EVVF centre, but even then, the one exception was supported by her family prior to failed quests for cure at other health facilities. The support finally provided to exact a cure at the centre for this woman was, a government co-sponsored fistula repair outreach, and through provision of transport fare. Family support has been noted as the prominent feature for accessing treatment by studies. Families provide financial assistance and serve as a physical escort to get to repair centres in countries like Tanzania and Malawi (Women's Dignity Project and EngenderHealth, 2006, Yeakey, 2011). Similarly, family support was also reported in a study in the south of Nigeria. Hence, if a woman lost family support due to their fistula condition they were likely to experience difficulties in receiving treatment (Yeakey, 2011).

The major barrier for women who lived with fistula for a long time before receiving care could be down to ignorance about whether the condition was curable. Efforts need to be intensified in overcoming this barrier. The source of information for repair was majorly from fistula survivors and hospital referrals. Fistula survivors turned community advocates have become repair information bearers, and this needs to be developed further into education strategies to outline fistula eradication and prevention strategies.

Only one woman who received government support for treatment (discussed above) had heard information about the support possibility through an announcement on the radio. Government need to play a greater role than is currently provided in raising awareness and providing support around receiving treatment.

The experiences of women who reported using OTC and traditional remedies due to lack of awareness of the availability of treatment or financial difficulties to seek orthodox care, reinforces the barriers to access to care. This was similarly reported in other studies (Women's Dignity Project and EngenderHealth, 2006, Mwini-Nyaledzigbor et al., 2013, Jarvis et al., 2017, Khisa et al., 2017a). Perceived fear of cost was a general phenomenon as initial thought on hearing of the repair centre was disbelief as to the free services at the repair centre. Perceived cost also has been cited as barrier to receiving treatment, hence the need to create more awareness about the availability of free treatment and seeking ways of addressing the major barrier of transport cost to treatment centres.

Co-morbidities particularly issues of sexual and reproductive health remained a challenge as has been noted in prior studies. Poor pregnancy outcomes, infertility and sexual health issues have been reported post fistula repairs (Wilson et al., 2011, Delamou et al., 2016, Kopp et al., 2017). A study at EVVF centre highlighted sexual difficulties women encounter after fistula repair; reiterating the need for inclusion of management of sexual dysfunction in rehabilitation post fistula treatment (Anzaku et al., 2017). The desire for children as was observed among the still married who experienced stillbirth was similarly reported in Tanzania (Mselle et al, 2012). A scoping exercise on pregnancy outcomes post repairs in Sub Saharan Africa revealed a paucity of evidence on pregnancy incidences despite that women still desired pregnancies (Delamou et al., 2016). The sexual and fertility difficulties are issues requiring attention in a context where women's value is rated by successful motherhood (Wilson et al., 2011). Mselle et al 2012. Further attention is advocated to address the sexual and reproductive health issues of fistula survivors

Even though access appeared quicker, repeated repairs were still required as was observed among the participants. Despite the repeated surgery, there were women with different levels of residual incontinence. Residual incontinence as was observed in

the study was reported in other studies (Drew et al., 2016, Wilson et al., 2016). Success as defined by women in this study was the return of control over incontinence, which remained the singular desire after every surgery that translates into unrestricted social interaction. Yeakey et al (2011) noted a similar description of success in surgical repair by fistula survivors in Malawi. Improved control for women with residual incontinence still resulted into improved ability to function, move around and interact socially (Yeakey, 2011). But the overall desire, was to achieve a dry status, hence the persistence in seeking a cure as was demonstrated with women still experiencing incontinence.

This persistence to obtain a cure signalled resilience on the part of women despite the repeated repairs. And even though some few women experienced a loss of family's support that was crucial for the first contact with the repair centres, such women thereafter continued in the quest for a cure singularly. In the study women exhibited great courage in persisting in receiving a cure. Only one woman had a single repair and became continent. The return of control resulted into a change from the negative identity. The 'improved' identity is the only positive identity that signals a change in the hitherto flawed bodily image and personality. Interestingly, the return of control of continence flow, after surgery whether it was change for a dry status or return of control with residual leakage was viewed as an improvement. The freedom from the burdens of fistula, that included unrestricted movement, resolved stigma (Drew et al., 2016) and return of self-esteem with the return of continence control was similarly reported as a sign of recovery by other studies (Wilson et al., 2016, Khisa et al., 2017c).

Treatment for participants included the rehabilitation program that provided counselling and income generating skills. The paucity of good qualitative research on experiences on rehabilitation care provided across centres was noted in a systematic review (Lombard et al., 2015). Receiving rehabilitation as a part of reintegration services in the treatment program was a beneficial boost to women in the study on all spheres of life. Studies in other countries identified economic empowerment and social acceptance as crucial for successful reintegration (Pope et al., 2011, Donnelly et al., 2015, Jarvis et al., 2017). Even though Nathan et al (2009) alleged that most of the women in their study after a successful repair did not require additional support. However, those that requested still sought financial support for business set up to

facilitate economic autonomy; thereby exposing the need for support for women to be financially empowered. Two studies in Nigeria and India evaluating the quality of life revealed that surgical repair alone contributed to improvement in physical, social and mental health domains with no significant improvement on the environmental domain (Umoiyoho et al., 2011b, Singh et al., 2015). Due to negligible impact upon the financial status of women the environmental health domain remained unchanged post fistula repair (Umoiyoho et al., 2011b, Singh et al., 2015).

On another hand, women in the study cited physical, social, economic and psychological benefits. Physical benefits described were initial support to commence business activities; the period of rehabilitation was an opportunity to recuperate, as well as skills learnt provided a less strenuous occupation for recovery. The social benefits included improved interaction and socialising in the pursuit of business hence self-isolation ended, while economic benefits for the majority were financial empowerment, self-sufficiency and autonomy, and the skills were acquired at no cost. Again, despite the inability of some women to utilise the skills for income generation purposes all women reported, mental benefits that included improved cognitive ability, mental capability, and the return of self-confidence. It is important to note here that three women returned to pursue (higher) education thereafter.

The challenges faced with utilising acquired skills were similar to those reported in a study in Ghana, which included difficulties in sourcing for raw materials and lack of acceptance of product by rural communities (Jarvis et al., 2017). It is therefore paramount that the 'one cap fits all' approach that is in practice be reorganised to tailor suit women's need and environment (Esegbona, 2012: 206). Additionally, even though women were happy to receive the skills, not all were able to afford the necessary equipment to use the skills acquired and hence returned to farming, making the training a wasteful venture.

The benefits received from the rehabilitation program confirms the value of providing the services, for the support in addition to healing the psychological injury, addresses the basic social aetiological cause of poverty (Yeakey, 2011, Esegbona, 2012). The benefits received qualify it to be considered as a social reintegration intervention; it

addresses physical, social, economic and mental multifaceted impact of fistula on women (Esegbona, 2012). Hence it is suggested that rehabilitation that provides income generating skills should be included in treatment management and women encouraged to participate.

In another dimension in this study, women with persisting incontinence despite several repairs perceived the income generating skills acquired caused the change in their financial status leading to the improved identity. This improvement was celebrated not only because it created an avenue for financial self-empowerment, but also that it provided the financial means to continue to seek cure that they desperately desire irrespective of spousal support. For instance, Maimuna reiterated that developing fistula the second time would not have happened if she had mastered the sewing skills learnt after the repair of the first fistula; for she would have accessed care instead of relying on her husband who did not have money to pay for her C- Section after her subsequent pregnancy. Financial difficulties were reported to contribute to fistula formation, hence financial empowerment through skill acquisition can serve as avenue to break the fistula cycle as proposed by social reintegration (Esegbona, 2012). Financial dependence on spouses reportedly complicates the power relations that limits women's behaviour in the social body (Hamed et al., 2017). The rehabilitation created an avenue for exposure and financial empowerment hence boosted women's ability to resist power relations in terms of self-autonomy. The skills acquired provided income generating enterprises; hence women became financially empowered and therefore could claim self-autonomy with respect to their health. All participants in the study with persisting incontinence no longer rely on their spouses to seek further treatment due to their enhanced financial position. Mohammed (2007) alleged that rehabilitation enhanced women's status hence they were not only financially empowered but were also better positioned for negotiations in their relationships. This experience highlights the benefits of skills acquisition in providing financial empowerment and self-autonomy for women, thereby highlighting another significant benefit of the rehabilitation service to fistula treatment.

6.1.4 Returning to Life

The return to life was processed based on the ability to function socially with renewed confidence when continence control was gained. All women evidenced the level of control notwithstanding, the ability to resume their normal roles and responsibilities and participate in social functions. A study by Yeakey et al (2011) similarly noted that cured women and women with improved (partial) control reported the change of status translated into improved abilities to function both physically and socially. The factors that facilitated the return to life in this study were – resolution of stigma after cure, family and community support. This study attributed successful reintegration to family support and acceptance in the community and corroborates similar findings in literature (Pope et al., 2011, Mselle et al., 2012, Landry et al., 2013). Family support consisted of providing care until stamina was restored and included the provision of food as well as facilitating personal needs and procuring equipment to commence small business enterprises.

Another significant contributor to resuming lives was the psychosocial support, specifically the EVVF valedictory ceremony and participation in the EVVF rehabilitation program. These were observed to be specific social reintegration interventions that mitigated the physical, social and psychological consequences of fistula that facilitated the normal living upon return home (Esegbona, 2012). The ‘freedom ceremony’ (as it is referred to by the centre) was a public declaration of victory over the condition and signals a return to normal life; additionally, for non-fistula patients to dance with women meant public display of acceptance. Dancing in public in Africa at gatherings, festivals or ceremonies; in this context is the celebration of the ‘rites of passage’ when an individual passes from one role to another, for instance in commemoration of births, graduation, initiation, wedding, election into political office, and deaths (Onwuekwe, 2009). The freedom ceremony signalled a return of health and acceptance back into society after a life of isolation and shame. The ceremony appeared to play a psychological healing effect on the process of return and reintegration as described in the narratives.

The benefits derived from the rehabilitation program were portrayed as valuable in the return to life process. One of the significant benefits was the change in financial status

derived from the acquired income generating skills. In addition to family or community support, other studies linked successful reintegration to the ability to work and the rewards of financial autonomy (Khisa and Nyamongo, 2012, Mselle et al., 2012, Khisa et al., 2017c). Developing fistula contributes to the precarious economic situation of women (Donnelly et al., 2015, Jarvis et al., 2017), particularly for those who were abandoned by their spouses and those without financial empowerment pre-fistula (Pope et al., 2011, Donnelly et al., 2015). Therefore, financial empowerment assisted significantly in elevating their status from a life of pity and shame to someone of productive value; hence their reception upon return to the community was good. This suggests that the elevated economic status facilitated acceptance upon return to the community. According to Mohammad (2007) rehabilitated women who return to their community due to their elevated status become sources of pride and happiness to their families and community.

Furthermore, in a context where economic hardship had been the norm, the change of economic status led some women to conclude the fistula was a 'blessing' in disguise as it led to financial autonomy and independence from relying solely on their spouses for daily sustenance. Interestingly for women in the study with persisting incontinence (as earlier stated) their ability to work and earn money was not only a consolation but ensured sustained access to health. Jarvis et al (2017) alleged that improved economic status of rehabilitated women resulted in improved access not only for the woman but also for her family. On the contrary economic difficulties for women who received only surgical repairs was noted to hinder reintegration in other studies, and was particularly worse for women with prolonged recovery (Khisa and Nyamongo, 2012, Mselle et al., 2012, Khisa et al., 2017c).

Again, in this study the income generating skills provided not only financial autonomy, but also opportunities for engaging in social activities. Women described increased movements and interactions in public places such as in catering and local brew businesses. This helped them return to normalcy and is a significant finding as hitherto they were unable to undertake these types of business ventures due to hygiene and self-confidence issues. In a study in Kenya, the lack of support and jobs to return to for treated women that did not receive rehabilitation led to self-isolation upon return to

their communities (Khisa et al., 2017c). The ability to work and generate income after fistula repair has been described by fistula survivors as important in reclaiming their position in the community (Muleta et al., 2008, Pope et al., 2011, Jarvis et al., 2017). Related to this is another benefit of rehabilitation, that of improved mental capacity and feelings of self-worth and confidence. For instance, three women went ahead to further their education post repair upon return to the community; thereby signalling the end to isolation and shame and a return to a normal but improved kind of living. These facts have not been reported by prior studies.

The period of training allowed for recuperation for some that eased resuming normal living; this period of recuperation was considered critical for full recovery post repair (Pope et al., 2011, Esegbona, 2012). For instance, authors suggest that the period could serve to accommodate the abstinence from sex enable proper healing and hence avoid difficulties some encountered from uncooperative spouses. The period of recuperation aided healing and prevented further damage when being transported back to their communities on bad roads. However not every woman was able to utilise the acquired skills, because of financial difficulties in purchasing equipment or raw materials and lack of awareness of the rural population for some of the products such as liquid soaps. Hence further work is required to develop their business acumen further and this aspect could be included in the centre's forward planning. In this instance, women returned to familiar work such as farming for sustenance of livelihood. Jarvis et al (2017) reported a similar concern in a study in Ghana; where women felt the skills learnt were not suitable for their physical and local economic condition.

Most women in the study returned to their primary communities, as similarly noted from studies in Malawi where women face fewer barriers to reintegration (Yeakey, 2011, Drew et al., 2016). On the contrary in a study in Ethiopia, women were unwillingly to return home and had settled into the urban life due to stigma issues (Gebresilase, 2014). Women who experienced difficulties in returning to normal living attributed this to the long recovery period due to post-surgical complications and repeated repairs that triggered stigma issues. The major stigma issues noted by women in the study were internalised stigma or self-stigma; as families appeared to support most women to continue to seek cure. Only one woman reported a total withdrawal of family support,

unlike the findings reported in a study in Kenya where women were labelled as cursed and sent away from their homes (Khisa and Nyamongo, 2012). Again, community labelling that contributed to marital breakdown was not widespread as only one incidence was reported in this study. Khisa and Nyamongo (2012) noted the community's negative view of treated women impacted upon a normal marital life despite successful repairs.

Other barriers to reintegration in the study were sexual and fertility issues for those women who were still married, and these contributed to tension in the family. Even though the fear of fistula recurring was evident for some women, the desire to regain reproductive capability in fulfilment of cultural norms was demonstrated in the study. This is not unique to Nigeria, as in other studies from Kenya, Tanzania, Malawi, and Bangladesh the authors also noted the difficulties with sexual intimacy and infertility that posed as challenges in fulfilling the social roles as wives and mothers (Yeakey et al., 2009, Khisa and Nyamongo, 2012, Mselle et al., 2012, Imoto et al., 2015). Successful return to life meant having children, hence the anxiety and feelings of pain exhibited by some women that had experienced child loss during the index pregnancy and who remained childless after repairs.

Childlessness led to spouses taking additional wives, which appeared to generate more worry for women in this situation hence hindering successful reintegration. Polygamy in response to sexual dysfunction and fertility issues post repairs has been similarly reported in other studies (Yeakey et al., 2009, Khisa and Nyamongo, 2012, Drew et al., 2016). However, three women out of the fifteen participants have had a successful delivery post repair; only one of these resulted in a fistula recurrence due to inability to pay for a caesarean section (she had not become proficient in the income generating skills after the first repair). Decreased pregnancy incidence and poor pregnancy outcomes (stillbirths and fistula recurrence) have been reported post fistula repair (Nielsen et al., 2009, Delamou et al., 2016, Drew et al., 2016). Unsupervised delivery post fistula most particularly results in worse pregnancy outcomes (Browning, 2009). Wall and Arrowsmith (2007) asserted that successful reintegration should entail restoring sexual function and improving future fertility chances as much as healing the

psychological wounds. Hence there is a need to stress the need for greater attention in addressing sexual and reproductive issues within fistula management.

Even though few women who were separated or divorced preferred their new status, women with children who lost their homes due to fistula and desired to return to their marital home viewed this as a barrier to return to normal life. As discussed under the 'spoiled' identity, this is a deviation from the expected and from prior studies (section 6.1.2). It is therefore suggested that tackling reintegration issues should incorporate addressing the 'spoilt identity' and the associated stigma effects. Counselling sessions should not just involve the women, but also include husbands, families and community members to address issues in pursuit of successful reintegration (Esegbona, 2012). Mselle et al (2012) argues that the focus of reintegration of women after treatment should not simply be on physical, mental and socio-economic needs but should also incorporate issues associated with the 'spoilt identity' and the cultural expectations of the society.

6.2 Part B - Theoretical Considerations

Studies on illness can expose the nature of the interactions between the body, individual and the society (Nettleton, 1995). Illness narratives as personal experiences are inseparable from the influence of the social and cultural changes on all levels ranging from the community to the global (Kleinman and Seemam, 2003). Illness experiences lead to the evaluation of the wider social context and embodied states (Kleinman and Seemam, 2003). To gain insight from illness narratives, three crucial levels of analysis are required, firstly the individual level of beliefs, attitudes and actions towards health and illness, secondly the social level which considers the interaction within and beyond the health care system and lastly the 'societal' or facility level which evaluates health policies and health reforms within the political context (Nettleton, 1995:8, Charmaz, 2000). Therefore, theoretical concepts that can analyse on these level have been selected to provide an understanding on the empirical data. Furthermore, as a narrative reconstruction, it is equally important to analyse how individuals make sense of their illness.

6.2.1 Fistula Experience and Illness Narrative Typologies

The first theoretical concept drawn upon is from Frank's wounded storyteller (Frank, 1995). Even though Frank's writings are based on cancer, the narratives of fistula survivors typify the wounded storyteller; where Frank (1995) describes illness narratives as stories recounted through a wounded body, which has personal and social sides. To provide an understanding of how the fistula survivors constructed and presented their stories, Frank's three typologies of narratives will be employed, they are restitution, chaos and quest narratives (table 6.1 below). According to Frank (1995: 76) all three narratives are told, alternatively, and repeatedly' in an illness experience, but at any point in time a single type guides the process which may change as the illness progresses (Frank, 1995).

Table 6 1: Frank (1995) Narrative typologies

Narrative typology	Plot line	Key characteristics	Fistula survivor's narrative
Chaos	Life not getting better	<p>Anxiety provoking</p> <p>Imprisoned body, loss of control</p> <p>Inability of medicine to control the ailment</p>	<p>First narrative typology</p> <p>Body awareness</p> <p>Loss of identity/ identities reconstruction based on incontinence flow</p> <p>Ignorant of availability of cure</p>
Restitution	"Yesterday I was healthy, today I am sick, by tomorrow I'll be healthy again"	<p>First and general story line</p> <p>Brought about by medical agency</p> <p>Increasingly restrictive in availability</p>	<p>Narrative typology with contact with treatment centre</p> <p>Hopeful for cure with (every) repair attempts</p>
Quest	Searching for a purpose	<p>A sense of purpose in illness experience as a journey</p> <p>Opportunity to amend what was not right</p> <p>Tellers of the view that insight gained should be passed on</p>	<p>Lesson about life; chastening to make amends about life</p> <p>Blessing from illness- opportunity to learn skills</p> <p>Advocacy stances- repair advocates; SBA delivery for child birth; women's financial autonomy through skills acquisition</p>

Source: Frank (1995)

It is important to reiterate here that Frank's narrative typology even though widely used in illness narratives in assisting listeners to hear stories, has no prior evidence of empirical testing on studies on women's health. Additionally, its use appears to be limited to studies mostly of cancer in the western culture, as there is no evidence to prove otherwise upon literature search. Nevertheless, a theory that reflects upon embodied experience like the narrative typology can provide an understanding on the process of sense making of the disruptive effect of obstetric fistula upon women's lives.

The restitution narrative according to Frank (1995) is the beginning and the most common among chronic illnesses, because anyone who is unwell desires to be healthy. Restitution narrative has a plot line of "yesterday, I was healthy, today I am sick, but tomorrow I'll be healthy" (Frank, 1995:77). Restitution is therefore a consequence of contact with 'medicine', which could be a surgical procedure or medications (Frank, 1995). On the contrary in the study, this does not apply, as access to health care is not as quick in comparison to the western culture, where Frank's illness narratives are situated. Again, women in the study were mostly unaware of the ailment hence thought there was no cure.

The delay in receiving care can be attributed to the poor health system and health seeking behaviour, mainly the issue of poverty and health belief in traditional medicine (TM). Nigeria operates a pluralistic health system, where orthodox and traditional medical practice operates alongside each other; as noted in the introduction (section 1.6.1). Some women reported visiting traditional healers due to financial difficulties or because they/and their families felt traditional remedies could provide a cure particularly because the condition was an unknown ailment, resulting from childbirth that is supposedly a natural process. Many ethnic groups across Nigeria hold the belief that illness could be caused by natural, or supernatural or mystical influences (Akpomovie, 2014). The TM perceived holistic approach to disease treatment is also perceived to contribute to its acceptability (Abdullahi, 2011, Adefolaju, 2014). Traditional Medicine is reported to be sought in disease or ailment conditions considered to be abnormal, hence demanding supernatural intervention (Abdullahi, 2011). Furthermore, TM are favoured in the rural areas, due to the lack of access to and prohibitive cost of orthodox medical care (Abdullahi, 2011, Adefolaju, 2014).

The chaos narrative, which Frank describes as the opposite of restitution, was the first and most common in the study; wherein the plotline was women bereft of the hope of getting better was the starting experience. Chaos narratives are typical narratives of loss of control, which Frank describes as being carried along “without control, by life’s fundamental contingency” (Frank, 1995: 102). Again, in Frank’s chaos narratives, the loss of control is complemented by the inability of medical attention to provide a cure, which was not in all the cases in this study. Women who despite repeated repairs remain incontinent therefore fit into this typology. In chaos narratives, the body suffers degradation by not only the ‘disease’ but by social ill- treatments, hence survival hinges on self-dissociations from the body, even though the suffering is all that represented the present life to the ill person (Frank, 1995). This was evident in the study, the loss of continence control spiralled into life changing traumatic events that had negative consequences upon all spheres of living. Words are lacking while “living the chaos”, and it is only retrospectively a reflection can be made of the experience; hence chaos can only be lived (Frank, 1995: 98). This was equally evidenced in women’s narrative; feelings of vulnerability and despair was demonstrated which resulted in some women considering suicide as an escape, while some others took consolation in their faith. Frank (1995) noted chaos narrative sometimes triggered an opening to faith for those inclined to do so.

The shift from chaos to restitution narrative began with contact with treatment (Frank, 1995). Hence restitution is a triumph for medical practice for women that regained a total dry status, as was noted by Frank. This can however not be said of women with persisting incontinence, who appear to fit into the typical chaos narrative of Frank as was earlier noted. For these women, they appear to be speaking with both the restitution and chaos voices. Restitution and chaos, according to Frank are background voices of the sufferer, while quest speaks with the voice of the ill person (Frank, 1995). In quest narrative, the teller takes hold of the suffering accepting the ill health and making a meaning out of it. Frank succinctly captures it thus “illness is the occasion of a journey that becomes a quest” (Frank 1995: 115); as the ill person gradually gains an understanding of the ill health, the journey begins. This was demonstrated by some of the women. The changes in their lives and identity were platform for gaining meaning

from the illness experiences within the context of their own life's experiences (Hyden, 1997).

Meanings were influenced by the "historical, cultural, social and situational contexts" (Chamaz, 2000 p.282). Hence seeing life in the light of the illness, the narrative was a turning point and an opportunity for reflection. Williams (2000: 137) describes this as efforts to turn 'the loss of meaning' to 'some sense of purpose' by the process of narrative reconstruction. Frank noted that this was a demonstration of "recollection, solidarity and inspiration" (Frank, 1995: 133). The narrators in the recollection of their memories take it as a responsibility to set better examples for others to emulate through the memories (Frank, 1995). In the study some women thought the experience was a chastening period for behaviour change, while others reflected that the bad experience turned out a blessing with the elevated status from acquiring income generating skills they did not pay to receive. The rehabilitation program can therefore be considered a part of the restitution story, as the income generating skills resulted into a transformation of identity. However, it did not address the physical health challenges rather, it helped women cope psychologically.

Additionally, in the quest narratives some women could proffer various suggestions from the reflections. These suggestions are represented as advocacy stance, which were: promoting awareness on surgical repairs for women living with fistula in the community. Frank noted that involvement in patient advocacy is an example of a quest narrative (Frank, 1995). Similarly, related was the promotion of skills acquisition; women that had benefitted from the skills acquisition lauded the rehab program and strongly believed women should take advantage of acquiring an income generating skill to improve the quality of their lives. Another one was the advocacy for utilisation of maternal health services by pregnant women: having understood the cause of their problem, women provided suggestions on ways fistula can be prevented.

The narrative types were thus demonstrated in the creation of stories by fistula survivors but not in the order listed by Frank. The health belief and health seeking behaviours wherein due to poor access to health and beliefs in traditional medicine is thought to have contributed to the differences in ordering from the western focused narratives that

Frank's typologies originate from. Furthermore, even though Frank noted one type may guide the story and change as the illness progresses, women with persisting incontinence appear to add one typology to the other on their illness experience which remains an on-going journey. The women yet remaining hopeful for a cure, appear to be creating chaos, restitution, and quest stories all at once, as they have not achieved full recovery.

6.2.2 Fistula and the 'three bodies' Experience

The socio-cultural context of fistula survivors played significant roles not only on how fistula developed but also in the experience of living with uncontrollable incontinence. The 'mindful body' theory will be utilised in providing an understanding on the role of the socio-cultural context on how bodies come to be constructed. According to Scheper-Hughes and Lock, the body is not only a physical and figurative artefact but are "naturally and culturally" created (1987: 7). On this basis, the mindful body approach using the "three bodies" levels namely "individual body", "social body" and "politic body" will be utilised to analyse fistula survivors lived experiences (Scheper-Hughes and Lock, 1987). The 'three bodies' even though separate, overlap (see figure 10 below) in providing an understanding on how the body is socially represented (Scheper-Hughes and Lock, 1987).

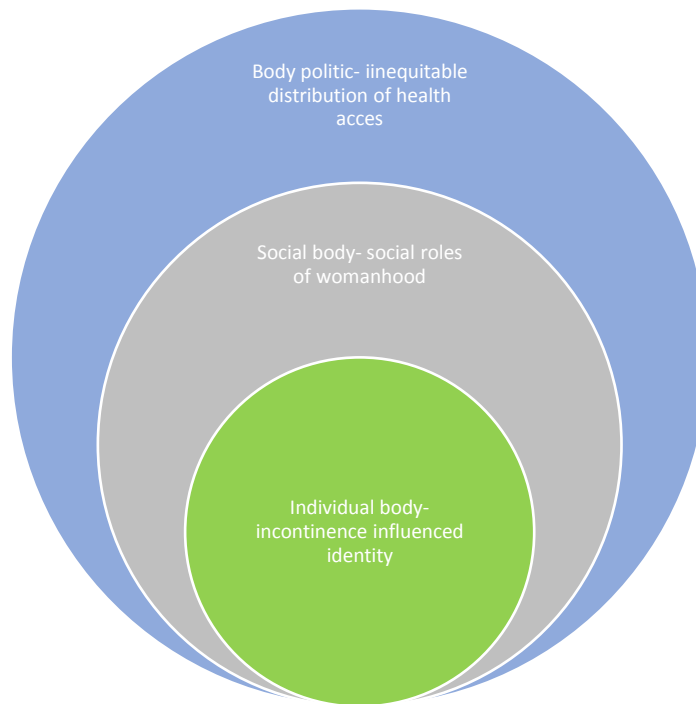


Figure 10: Bodily experience of fistula and fistula formation

The individual body – is the first and most evidential level of the bodies that is presented, as it represents the lived experiences of the self in the body. This was how the different parts of the body – “the mind, matter, psyche, soul, self, etc.” related to each other and the way body manifested in the illness (Scheper-Hughes and Lock, 1987: 7). The narratives reflected women living life in a body that had been crippled by the fistula; the uncontrollable incontinence caused a new experience of living with a body that leaked as well as smelt, thereby impacting not only on the physical condition of the body but also that of the mind. As earlier described, the experiences of living with fistula had physical, psychological, social and economic consequences upon each woman. Scheper-Hughes and Lock (1987) noted that in Japan, the family is the most fundamental unit of the society rather than the individual, this is similarly so in most African cultures (Ekane, 2013). In Africa, collectivism rather than individuality is the typical characteristics of the community structure (Ekane, 2013). Hence women’s view about their ‘individual body’ was linked with how others perceived them and how it affected their daily social functions (section 5.4.2, p.186).

The social body- this reflects the exchange between the body as a natural symbol and the social worlds (Scheper-Hughes and Lock, 1987). Furthermore, the natural secretions

of the human body such as blood, tears, semen, milk, faeces can be used as “cognitive map” to symbolise “other natural, supernatural, social and even spatial relations” (Scheper- Hughes and Lock, 1987: 19). The uncontrollable incontinence flow of urine or faeces formed a barrier to social interactions for every woman. In every society, all humans in socialising their culture has imbibed appropriate cultural norms of how to regulate and take control of bodily boundaries (Lupton, 2000). The flow from inside to outside of loathed bodily fluids at inappropriate times arouses disgust (Lupton, 2000). The compromised hygiene because of the uncontrollable bodily secretion meant an enhanced perception of abnormality and limitation in social relations to avoid offense and feelings of shame by women.

The experience of living with the social body was also due largely with how the society construed the body to be lived. The ill body represented a model of social disharmony, conflict and disintegration (Scheper- Hughes and Lock, 1987: 7). Cultural connotation of and concerning the body are important in maintaining societal views and directing social relations (Scheper-Hughes and Lock, 1987). Fistula ruptured physically and functionally the anatomy that symbolises femininity. The social body is the most prominent of the three levels, as in many African cultures, motherhood defines womanhood (Devi, 2017). In this context the limited social interactions were due not only to change in woman’s body but also because of failings in social responsibilities and expectation of womanhood. Childlessness in the Nigerian context is viewed as a grave failing on womanhood. This failing in social roles and responsibilities was more obvious for the married women. For instance, on the family level, married marital life was disrupted because of sexual difficulties and infertility issues. A typical response of how community viewed infertility was demonstrated by a participant who reported how she was told her inability to conceive was responsible for her failed second marriage (section 5.6.3, p.224).

The body politic- refers to the regulation and control of bodies, which could be of an individual or as a group, in reproduction, sexuality, in work, in relaxation, in ill-health and other forms of conformity and human difference (Scheper-Hughes and Lock, 1987). The body politic reflects power and control between the body politic and the individual body. For this study, this was reflected by the gender imbalance in the position of

women in the society; the lack of women's autonomy to seek health. Cultures dictate the regulations and social scripts for the domestication of the individual body in compliance to the needs of the social and political mandate (Scheper-Hughes and Lock, 1987). Scheper-Hughes and Lock (1987) further describe body politic as government control of reproduction of not the individuals but of the whole population. However, the control of reproduction by the government in this study differs from that described by Scheper-Hughes and Lock; rather it was reflected by the lack of 'support' for reproduction by the absence of adequate maternal health care system in rural communities that contributed to fistula formation.

6.2.3 Fistula and Stigma Management

Stigma is the possession of attributes viewed to be greatly discrediting (Goffman, 1963). Individual labelling ensues; however, the experiences of stigma occur in interactions and relationships (Charmaz, 2000). As a typical social process, it results in 'exclusion, rejection, blame or devaluation' by a person or group. Stigma can inflict chaos upon self-forcing objectionable new ways of perceiving self and circumstances (Charmaz, 2000). The consequence of living with fistula results in both physical and social disabilities (Yeakey, 2011). As highlighted in section above, the stigma issues that arose in the narratives bordered on interactions with others. Stigma issues surrounding fistula formation has been widely researched in studies on experiences of women with fistula before and after treatment, particularly with respect to its effect on relationships (Bangser, 2006, Women's Dignity Project and EngenderHealth, 2006, Turan et al., 2007, Muleta et al., 2008, Nielsen et al., 2009, Pope et al., 2011, Khisa and Nyamongo, 2012, Farid et al., 2013, Siddle et al., 2013, Mwini-Nyaledzigbor et al., 2013, Gebresilase, 2014, Donnelly et al., 2015, Jarvis et al., 2017, Khisa et al., 2017c).

Stigma is a generally known consequence of chronic illness and it is fixed threat to some individuals' perception of their illness experiences (Charmaz, 2000). The experiences of stigma by women in the study are a typical consequence of chronic illness conditions. The incontinence flow as the 'stigma symbols' conveyed the 'social information' which in the case of women was visible (wetness and smell) this therefore becomes the women's social identity that triggers stigmatisation (Goffman, 1990). The visibility of the stigma symbols in affecting/ interfering with interactions determines the extent of

stigmatisation (Goffman, 1990). Charmaz (2000) described two types of stigma, namely enacted, or felt. Enacted stigma is act of discriminating against people considered to be different, while felt stigma results from fear of discovery and shame of being different. Both types of stigma were described in the narratives. Women described feelings of shame, and feelings of being reduced from who they were to someone of no value. Goffman (1990) describes shame as a dominant possibility when an individual perceives they possess attributes considered to be defiling. The shame of loss of control over bodily function in public that constituted hygiene issues led to restriction of movement. The high 'visibility' of the stigma symbols therefore warranted a total self-isolation as some participants reported. Restrictions of movements and social interactions are ways of managing felt stigma (Charmaz, 2000). Questions of 'why me?' or 'what did I do to deserve this?' were asked. Anger and sadness were also demonstrated when faced with stigma actions. Charmaz (2000) attributes these questionings and feelings to individuals' reactions to acceptance of the moral accountability rooted in collective representation of illness. Equally in what is suggestive of anger and frustrations against continued stigmatisation in public, a woman reported resorting to challenging comments about the smell of urine on a public transport, while another supposedly ignored stares and comment about her leakage by moving around unashamedly. Stigmatised persons instead of cowering could challenge stigmatising attitudes by 'hostile bravado' (Goffman, 1990: 29).

In describing the experiences of extreme shame and stigma however, fistula survivors have been described in research as "poor little girls", "the wretched of the earth", and "women who cannot even be successful prostitutes" (Bangser, 2006: 535). With regards to this Bangser (2006) argued that in framing public understanding on stigmatisation such description deserves to be based on fistula survivors' perception. Again, research on the lived experiences of women with fistula is typically constructed to be synonymous with "divorce, shame, isolation, stigma and cessation of sexual activity" (Yeakey et al, 2009: 500). In this study, not all marriages were disrupted after fistula development, and even though sexual activity was affected it continued for some women even before treatment. This was similarly reported in some earlier studies (Women's Dignity Project and EngenderHealth, 2006, Bangser, 2007, Muleta et al., 2008,

Pope et al., 2011, Heller and Hannig, 2017). Yeakey et al (2009) were of the view that marital continuity; remarriage and spousal support were usually not discussed in research-driven constructions of women's experiences of living with fistula. Heller & Hannig (2017) purported that reports of blatant discriminations where women were portrayed as outcasts, social pariah, divorced, shunned and isolated by both kin and community were media and donor strategy to sensationalize fistula narratives for popularity and financial gains (Heller and Hannig, 2017). It is however important to note that none of the women in this study experienced total stigmatisation or shunning as some studies noted. Some forms of support appear to be present when stigmatisation was experienced in this study.

The differences in stigmatisation experiences from extreme to minimal might be context related; differences in culture and beliefs in relating with persons with debilitating conditions such as fistula could be responsible. According to Charmaz (2000) how, when and whether people acknowledge and behave in illness is culture and context specific. Furthermore, increasing access to treatment and growing in awareness on the availability of cure might be responsible for differences in stigma experiences. However, it is important to reiterate here that, stigmatisation still does exist and needs to be properly addressed as women deserve support for productive living. Women that reintegrate successfully after repairs had acceptance from both family and community (Pope et al, 2009). Additionally, fear of stigmatisation has been reported as one of the reasons, which prevent women seeking treatment (Warren et al, 2016, Baker et al, 2017).

6.2.4 Coping Mechanisms

To cope with the challenges of living with fistula, different strategies were employed (Section 5.4.3, p.195). This is a typical reaction in stigma management to conceal or eliminate stigma symbols that could potentially provide a discrediting perception of self (Goffman, 1990, Charmaz, 2000, Mselle et al., 2012). Coping efforts serve to manage the 'person- environment relationship', which is the source of stress and regulate the associated stressful emotions (Folkman and Lazarus. 1980: 223). Women's lives upon development of fistula revolved around strategies of preventing the incontinenes being

noticed, reduction of smell and maintaining relationships with their spouses, relations and community members (Barageine et al., 2015). Folkman and Lazarus (1980) identified two coping processes; namely the 'problem focused' and 'emotion focused' functions that were found applicable to the coping strategies employed in the narratives. Based on Folkman and Lazarus, the emotion focused approach was self-isolation, detachment- restriction of movements and socialising, humour, and apportioning of blame to self or others. Problem solving strategies utilised include seeking information and help, restricting action and taking categorical action; moving around facilities for a cure, in this case the use of physical barriers to inhibit the incontinence flow (like rags for padding), and incessant washing of clothes.

Another coping strategy playing a prominent role in the discourses was religious coping as women freely and frequently referred to their hope in God, and how they resorted to prayers for a cure. The feelings of anger against God (which women claimed they later repented of) or harbouring unwholesome thoughts/negative thoughts were dealt with afterwards with repentance. Some others felt it was a cleansing period; an opportunity to make amends in their lives. Religious beliefs are reported to have impact upon coping by women with chronic illness. The society is highly religious as such this was not unexpected. Religious coping was similarly described in studies in Nigeria and Tanzania as important factors in dealing with challenges faced while living with fistula (Watt et al., 2014, Okoye et al., 2014). Despite women's religious commitment, women did not appear to have benefited from a structured religious support in alleviating the effect of stigma while living with fistula, apart from references made of reaching out to celebrate recovery in church by two participants. Fears of embarrassment in religious gathering instead hindered or limited attendance while living with the condition. Meanwhile Watt et al (2014) argued that in religious communities integrating religious frameworks could help mitigate the effects of stigmatisation in the community through the efforts of religious leaders.

The coping strategies provided a structure and support for the day-to-day living with the condition. The 'emotion focused', 'problem focused' strategies and the religious coping put in place by women reduced the boundaries between the individual and their environment. It is therefore suggested that the religious leaders be more involved and

strengthened through education on avenues to provide support to fistula survivors and addressing stigmatisation in the community.

6.2.5 Health Interactions

The Cultural Health Capital (CHC) theoretical concept provides an understanding of the patient – provider interactions that contribute to health disparities (Shims, 2010). It highlights the influences of patient – provider interaction in fistula treatment. According to Shims (2010), holders of CHC are not free will individuals with autonomy to acquire and use resources at will. This was demonstrated by women’s powerlessness in seeking care that led to fistula and further highlighted in seeking treatment for the condition; Women that accessed care had support to do so. Cultural Health Capital examines the interactions on two dimensions (figure 11 below).

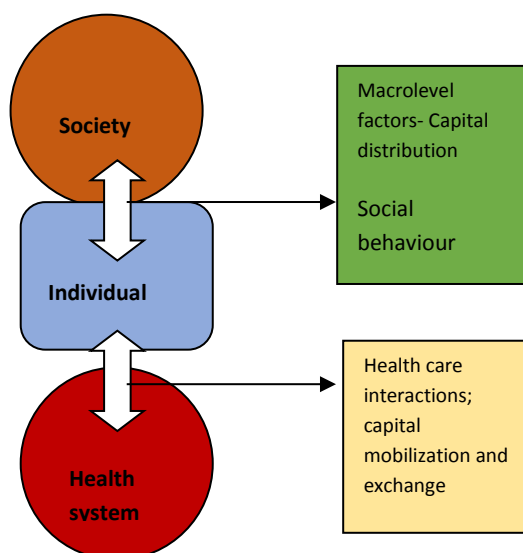


Figure 11: Influence of society and health system on the Cultural Health Capital

Society: Upstream on the macro level are factors that organise the distribution of capital and downstream in the direction of health care interactions where capitals of all forms are mobilized and exchanged. In CHC, health outcomes are linked to social conditions and “existing distribution of knowledge, money, power and other social conditions” thereby magnify existing inequalities (Shim, 2010: 5). Again, within the notion of CHC lies the Bourdieusian idea of actors possessing habitus rather than being capable of fulfilling consciously and deliberately planned targets (Shims, 2010). Habitus is a set of

personalities and styles that tilt but do not predispose how one will behave in different conditions (Bourdieu, 1977, 1980). Habitus influences the order, form and shape of actions, furthermore social stratification is significantly linked to habitus, acting as a constraining factor on individual thoughts on what is felt to be theirs or not (Bourdieu, 1977, Shim, 2010). In the study women were of low educational background; only two women had completed secondary school (table 5.1). The others were either primary or non-literate. In the narrative the low-class status of women was evidently displayed by the lack of financial capacity to seek care and had to rely on family to provide the necessary support. In instances where cure was delayed, and family support became strained, women had to resort to other means such as begging to get funds.

Health system: The dynamics of the patient provider interaction that was considered is from the reflections of women on their experiences during treatment. CHC is thought to influence quality of care based on health providers and patients' communication and interpersonal dynamics (Shim, 2010, Dubbin et al., 2013). In understanding the patient's habitus; the picture of interaction provided by the narratives illustrates women who were at their wits end with an unknown condition until they arrived at the repair centre, and hence were more than happy to receive help that they hitherto had thought was none existent. Furthermore, treatment was provided free of charge and which was not in the usual character of practice in receiving medical care. Health services are user fee acquired hence contributing to the wide disparity in health that contributed to the development of fistula in the first instance. The experiences of women on contact with fistula repair centre differs in certain ways from that presented by women in a study in Kenya, where authors alleged the health care system was non-responsive in treating women with fistula (Khisa et al., 2017a). Even though most women in the study like those in the Kenya study had multiple repairs before regaining continence control, women in the Kenya study lived longer with the condition and had among other issues paid for their repairs (Khisa et al., 2017a). Hence the differences in patient-provider response between the studies.

Women with persisting incontinence even though grateful for the improved control appear to possess another interesting discourse on the patient- provider interaction. The case of Halima who decided not to reveal the actual number of repairs to her current

health providers based on her fear of stigma/ discrimination, speaks volumes of her interpretation of the system; in her attempt at stigma management displayed by information control to navigate the system. Halima's fear of stigma in revealing the actual number of repairs might be based on past experiences in seeking care at other centres or perceived fear that it might hinder opportunity for further treatment while still seeking for a cure. Studies claim shame and fear of stigma inhibits women in seeking cure (Warren et al, 2006, Baker et al, 2017). As such addressing stigma as earlier stated would therefore improve access to treatment for women who feel inhibited due to this.

6.3 Conclusion to Chapter

Women's experiences of living with fistula, examining the history, social structures, cultures and beliefs within which the experiences occurred was discussed in this chapter. Findings were discussed along identified plotlines with respect to existing literature. Additionally, further understanding was provided using theoretical concepts; Frank's typology of narratives provided an understanding on how women constructed their stories, while the 'three bodies' by Scheper-Hughes and Lock (1987) was used to provide an understanding on the role of the socio-cultural context on how bodies and identities come to be constructed. CHC highlighted the patient-provider interaction; reinforcing the influence of gender inequity in health access due to women's low status, nevertheless contact with health providers facilitated recovery at repair centre. The theoretical concepts of stigma and stigma management, and coping mechanism provided an understanding on the process of living with fistula. In the next chapter, which is the conclusion to the thesis, a summary of the findings will be discussed.

CHAPTER SEVEN

CONCLUSION CHAPTER

7.0 Introduction to Chapter

In this chapter a conclusion will be drawn on the study and this is presented as obstetric fistula survivors' narrative. Equally, the role of the author's reflexivity in the study is also discussed in the chapter. Additionally, this chapter presents the contributions to knowledge and the limitations of the study. The implications for research, practice, and policy development are also presented in this chapter. These implications are structured into interventions that are suggested at the health facility, government and community levels and the recommendations for future research.

7.1 Obstetric Fistula Survivors' Narrative

The stories of fistula survivors have been presented as a narrative through the process of restorying that seeks to give a sequence of beginning, middle and end to a series of events in the lives of women that develop fistula sustained from childbirth injuries. For the purpose of a clearer understanding, the narrative that has been reconstructed will be discussed under the headings of chaos narrative of fistula survivors and restitution/quest narrative of fistula survivors.

7.1.1 Chaos Narratives of Fistula Survivors'

The beginning of the chaos story for women was the birth experience that led to the development of fistula. The social, historical and cultural factors demonstrated the interplay/link between the individual, the social and the society on the experiences of developing fistula; clearly depicting 'structural violence' in the 'three bodies' experiences. One of the evidences of structural violence was women's limited access to maternal health services; due largely to poor health care system in rural locations. The second evidence was lack of autonomy to seek care as a result of poor financial capacity and cultural factors that limited women's decision making powers. Rural health centres were found to lack the equipment and qualified staff to provide emergency obstetric

care; the only solution to obstructed labour. Another factor of great influence was due to geographical locations and poor transport issues, further delays were experienced in arriving at the health centres to receive appropriate care. Equally, arrival on time at health centres did not guarantee receiving appropriate intervention.

The major issue was that of financial difficulties; and due to the inability to afford the fees to pay for services women resorted to home deliveries facilitated by TBAs and SBAs. A worrisome development about the SBA in homes was that their professional identities could not be confirmed. The non availability and lack of access to health services in rural health communities was evidenced in women's chaos stories as a major factor in the development of fistula. Women's final destination to receive emergency obstetric care were all located in urban centres. This clearly is a failure on the side of the government with the inequitable access to health care as was depicted in the study. Thus, the 'body politic' role of Nigeria's poor health systems in contributing to the poor maternal health indices and obstetric fistula development was evidenced in this research (see section 1.6.1 and 1.7.1, p.38 and p.44). Clearly, Nigerian government has failed to deliver on fairness and equitable access to health care services on the framework of Universal Health Coverage by WHO.

The cultural factors that limit women's decision making power and early marriage was equally demonstrated. Two young women were compelled by the influences of their mother in laws to seek home delivery. Even though these were not the major factors in the study, again this is currently been disputed by some authors who asserted that lack of access to emergency obstetric care in rural location is the major cause of fistula as earlier discussed (see section 6.1.1, p. 227).

The chaos story continued with the commencement of the uncontrollable incontinence flow. The effect upon the lives of women were again linked with self ('individual body') and 'social body'. Fistula formation triggered series of untoward consequences that impacted upon the physical, psychological, social and economic spheres of women's and their families lives. Coping with incontinence required devising both physical and psychological measures, prominent among these was the religious coping mechanism. The incontinence triggered a change in perception of self identity which was

precipitated by the existing social structures of family and societal expectations of womanhood. While living the chaos life, there was evidence of stigmatisation as well as evidence of support by either family/and or community members for women. The negative identities portrayed as 'leaking', 'masu yoyon fitsari' (leakers of urine group) and the 'spoiled' identities were reflections of the changes fistula had inflicted upon women. The 'spoiled' identity appeared to impact upon women's reintegration experiences after treatment, highlighting the significant role the social body played. Women with sexual and reproductive health difficulties experienced lingering challenges with family life as they tried to cope with their social responsibilities in daily living as wives.

7.1.2 Restitution /Quest Narratives of Fistula Survivors'

Women mostly reported getting information about availability of cure from fistula survivors (the 'masu yoyon fitsari'), who also served as care providers in the centre. The 'masu yoyon fitsari' even though a negative identity is therefore the beginning of the restitution story. As joining 'masu yoyon fitsari' officially upon arrival at the repair centre signalled the development of hope and sustained resilience to continue to seek a cure when treatment failed. Most women lived with the condition for less than a year before receiving treatment unlike what was reported in literature of other countries. Access to repair centres were majorly facilitated by family support; who financed the transport cost. Womens' low status in the social stratification limited their initial contact to receive treatment, exposing further the inequitable distribution of health access in terms of socioeconomic status and location.

The patient – provider interaction after contact with health care in the study does not portray a negative provider habitus that impacted upon the CHC to inhibit provision of quality care. Treatments were all received cost free, and women mostly received more than one repair to become continent. Treatment led to a change in perception of identity; an 'improved' identity represented the return of control over continence flow. And even women with persisting incontinence despite series of repairs maintained their restitution story line of "Yesterday I was healthy, today I am sick, by tomorrow I'll be healthy again" (Frank, 1995: 77). The rehabilitation program which was a part of the treatment services received played a significant role in the restitution story for women.

Benefits from participation in the rehabilitation program were alleged to aid reintegration after treatment. For women with persisting continence, the financial empowerment received from the acquired skills meant a sustained opening to continue to seek cure, as their status had been elevated to one with financial autonomy. However, for some the skills acquired was not beneficial due to inability to purchase equipments, raw materials and lack of market for products.

Reintegration for all women is ongoing, as such it is a restitution story. Interestingly, the role of the EVVF centre's freedom ceremony before discharge home as part of reintegration was lauded as beneficial; women claimed it facilitated psychological healing for the process to return home. Principally however, the determining factors on resuming life upon discharge, were the level of control of continence flow that was restored after repair, and the support received from mainly the family. Community acceptance for women was the demonstration of absence of stigma. The improved continence control led to a great extent the resolution of felt and enacted stigma, hence the freedom to move around. In addition to the elevation of status that financial empowerment received through the rehabilitation program, social interactions were restored as women had to move around to participate in income generating activities. Additionally, the time spent at the rehabilitation centre had assisted in the required recuperation period so normalcy returned fast for some.

The women with persisting incontinence however did not all return with much joy. Persisting incontinence was found to hinder reintegration, in a similar vein long recovery periods for women that experienced multiple repairs or faced post repair complications; the long wait had disrupted their lives and families'. Women with 'spoiled identity' also view this a hinderance to reintegration. In a society where womanhood is defined by motherhood, women that remained childless have found family living a challenge. Equally, but contrary to prior studies, some women with living children prior to developing fistula still could not be restored to their families despite their wish to, after receiving a cure. However, resuming life for some was a quest story, as women sought to turn their experiences to make a change upon others; through providing information for repair to women with condition, another quest story was advocating for women to become financially empowered through learning income generating skills. And yet

another quest story was that advising women and families to encourage SBA for births in the hospitals instead of traditional practices to prevent fistula development.

7.3 Contributions to knowledge

The study makes a significant contribution to the understanding of the lives of obstetric fistula survivors. The contributions are as follows:

1. This research is the first known comprehensive empirical study of the experiences of women with obstetric fistula, treated and rehabilitated in Nigeria. The study therefore contributes to the empirical evidence of women's pathway through developing fistula, to treatment and the life after treatment. Exposing the prevailing pertinent factors on how Nigerian women experience fistula.
2. This research is the first application to women's health in African context of Frank (1995) narrative typology.
3. The deviations from Frank's narrative typology order of restitution- chaos- quest, was linked to differences in health belief and health seeking behaviour. In the narratives, chaos story formed the beginning of the narrative for all women, followed by restitution and then quest. However, women with persisting incontinence, demonstrate all typologies at the same time.
4. This research is the first application of Cultural Health Capital theoretical concept in understanding patient- provider interactions in women's health matters in an African context.
5. In the application of CHC to women's experiences; it buttressed the role of women's limited autonomy that served as a hindrance to health care with regards to seeking treatment for fistula. But on the other hand, the provider's relationship with patient was devoid of non-responsiveness that could constitute a hindrance to treatment utilisation.
6. The three bodies' theoretical concept highlighted the role of sociocultural context in formation of fistula. The 'individual body' experience, how women experienced living with the bodily changes was more linked to the 'social body' due to the societal

expectation of the role of a woman. The 'body politic' highlighted the role of the government in health inequity in Nigeria that contributed to the development of fistula.

7. The use of SBAs in assisting child delivery in rural communities has not been previously reported; which could demonstrate a change in trend from TBA assisted births. Professional identity of the SBA was unknown, hence highlighting the need to identify/tackle the trend to exclude professional malpractice that could compound the challenges surrounding home deliveries that is already an issue contributing to maternal mortalities/morbidities.
8. The EVVF centre's freedom ceremony reported to contribute to psychological healing for return process to community after treatment. The impact of a ceremony like this, has not been noted by other studies as beneficial to reintegration after treatment
9. This research is the first empirical evidence of the benefits of rehabilitation (Income Generating Activities) on the long-term post fistula repair in Nigeria. The benefits were physical- material support provided income generating skills that aided employment prospects, which served as an avenue for recuperation following fistula repair or the development of coping mechanisms when repair failed; social - improved socialising in the pursuit of business hence self-isolation ended; psychological- improved mental capacity, improved feelings of self-worth and self-confidence; economic- financial empowerment, and self-autonomy was achieved.
10. Further empirical evidence of the benefits of rehabilitation in the case of women with persisting incontinence, the assurance and opportunity for continued access to care due to the income generating skills received that contributed to financial empowerment and self-autonomy.

7.2 Author's Reflexivity

7.2.1 An inside view of fistula survivors' experience

A grown-up woman like me waking up in wet rags every day is really a problem that is why anywhere you heard there is possibility of getting help, you have to rush there.

The motivation to do this study did not prepare me for the intensity of the emotional pain experienced during the interviews. As I became involved in the lives of each woman as their stories unfolded, it was the most heart wrenching experience I have ever had. The quote above is one example of the heart-breaking words I heard while listening to women narrating their stories. It took a lot of effort not to weep while women narrated their experiences. The most difficult part of holding back tears was when two of the women broke down, and I had to maintain with great difficulty an empathetic posture. However, each night in the quiet of my bedroom, the tears flowed. As I read through the transcripts and listened to the voices the tears flowed. Moreover, in my heart, all I could feel was 'no one deserves this', or 'it could have been me, for no one chose where to be born or to which family'. As I thought more, and reflected more on the experiences, I realised also the women had moved on and were moving on with their lives. The women did not want to be pitied but wanted to find a lasting solution to cope with their lives.

This experience was part of a learning curve, but the lessons did not come too quickly. I returned to the UK with the whole stories weighing so heavy on my mind that I was drained emotionally. My supervisors and friends suggested taking 'time off work and relax'. This helped to ease off the tension, but what helped the most was the realisation that each woman was living her life as best as she could. Gradually as I reflected on the experience, I truly agreed totally with the women that life goes on, but change is required. It was comforting to know some of the women have started this change by challenging the norm and standing up for women to be financially empowered and by seeking cure for women with fistula. The experience of researching into the life stories of obstetric fistula survivors was physically and emotionally demanding as I become emotionally enmeshed in the participants' life stories. This led me to making comparisons between the women's lives with those of my own life events and provided me with the opportunity to truly empathise with their plight. It also brought the

realisation that these women, like myself, had the resilient ability to move on with their lives despite the difficulties they faced. Like the women, my resolve to make a change has been strengthened with this experience. Hence, the experience has transformed my outlook and strengthened my quest to enable transformation during and following devastating experiences.

In the data collection process, due to the “relational research” approach of narrative inquiry, building up rapport between myself and the participant was viewed as crucial in capturing the true essence of stories the women had to tell during interviews (Clandinin and Caine, 2008: 545). Even though attempts were made to make the relationship non-hierarchical, the initial interviews were slightly awkward, because they were conducted with a research assistant present because of the assistance needed with the native language. Subsequently, the women were willing to share their stories, but with some reservations. This was made more apparent after going through the first transcripts with my supervisors. Thereafter, attempts were made to reduce this researcher-participant ‘distance’. I started visiting and joining in activities that women were doing at the rehabilitation centre. This entailed lengthy times of just sitting and discussing issues non-related to research. On other occasions, I chatted and joined women as they made bead jewellery. Equally during the reunion program of the EVVF centre that coincided with the data collection, I joined in the funfair activities of singing and dancing with women. The rapport development was evidenced by my name change, as I was now being referred to as mummy/auntie ‘mai tambaya’. Afterwards, women were more forthcoming in their narratives during interviews, some coming up to add more information to what was already said. And going back in 2017 for the annual reunion program of EVVF centre, I took the opportunity to carry out a debriefing and member validation; extra pieces of information was provided to add to the research that was helpful. For instance, Halima provided the true figures of the number of repairs she had received. Margaret provided more information about circumstances surrounding the choice of home delivery. My experience of undertaking this research has forged new friendships as I have maintained contact with the participants and I am aware of the changes in their lives.

These experiences assisted me to navigate the insider/outsider dichotomy. The insider role status allows access to a greater depth of data as participants are more open (Dwyer and Buckle, 2009). Paying attention to participants', outsiders' and the researcher's emotion as a valuable data, enriches the data process and deepens the analytic process (Copp, 2012). Dealing with the emotional pains I experienced has helped increase my empathetic approach towards the plight of women and strengthen my non-judgmental interest and openness in relating with participants thus enhancing a greater understanding. Empathy development for the social and personal lives of participants facilitates a broader understanding of social life in general (Given, 2008). Hedican (2008) asserts empathy development is assisted through maintaining perspective but finding ways to look beyond objectivity, whilst remembering and focusing on the goals of the research. However, as I discovered, maintaining objectivity to attain research aims comes at an emotional cost for the researcher.

7.2.2 Positioning and Writing

My motive in researching this area of women's health was to provide evidence that exposes the devastating effects of obstetric fistula, and how access and management of care for women with fistula can be improved. The write up of the research was undoubtedly partially shaped by my personal experiences, intellectual background and motivation for the study, as well as my personal encounter with women on the field. As Elliot (2005) stated this section on reflexivity is not an attempt at providing a 'confessional' statement of my experiences in carrying out the research, rather it is to provide an analytical discussion of how my biographical and theoretical views might impact upon my relationship with participants; the interpretation of the empirical evidence and the way the research is presented. Furthermore, reflexivity practice is essential in narrative inquiry for it is part of the ways of strengthening validity of the findings of the research (Riessman, 2008).

The choice of narrative inquiry methodology for the research, was premised on the fact that one of the key features of narrative inquiry is the desire to empower the participants, allowing them to develop the most significant themes in the study (Elliott, 2005). Additionally, as noted earlier, storytelling is a common African tradition, that dates a long time back; was thought to be an adoptable way of conducting the research.

In narratives interviews, internal validity is improved because participants are empowered to give more tangible and exact details about the topic in their own words in describing their life experiences (Elliott, 2005). Therefore, allowing the voices of women to be heard through the stories of their experiences of living with fistula was thus put at the central core of designing and carrying out the research.

In the choice of an analytical method among the different narrative analysis methods, a conscious effort was taken to select one that allows stories to be 'heard'; which was the emplotment and core story creation approach adapted by Emden (1998) from Mishler (1985) and Polkinghore (1988) works. Narrative according to Emden, is a "collective stored wisdom" of peoples' individual story (1998: 35). Hence, this narrative analysis method was found suitable because specific attention was paid on narrative development as a method of providing structure to individual stories. The core story creation part of the analytical process, allowed a total immersion into the stories, as it involved working to reduce the longer story into shorter versions using an 8 steps approach. Emplotment, the second part of the analytical process provided another opportunity for deeper immersion into the stories. While creating the story, it required identifying plots that weaves events together in a manner that exposes the essence of the story (Emden, 1998). Identifying these plots required taking into cognisance the social and historical context in which the events occurred, and recognising the implication of unique occurrences (Emden, 1998). The plots give order to complex events and how they interact. Therefore, in moving back and forth across the core stories, subplots and plots were identified; while comparing and contrasting important features to see whether they were common to all the women's stories, the three plots of fistula ordeal, treatment process and returning to life were identified. These plots fitted the narrative structure of a "temporal succession and causality" (Elliot, 2005: 7); the fistula was the beginning of the story, this triggered the series of events that makes up the 'fistula ordeal', then next the treatment process- in response to fistula developing and then after treatment the returning life. Even though not as simplistic, the sequential order of a narrative structure, was evidenced in the plots which is, a "beginning, a middle and an end" (Elliott, 2005: 7).

Another significant issue was, ensuring that the nuances of the language were not lost in the process of translation. Working with translated interviews into English involves challenging interpretive decisions (Riessman, 2008). As a non-native speaker, this was an initial issue of concern and that was why a native speaker research assistant was trained to assist in the interviewing; to ensure the right tone was set for the interview and language was not a hindrance in asking the questions or providing prompts to facilitate a continuous flow of the story. Most importantly, a native speaker that has a versed experience in health research transcribed and translated the transcripts. Equally being that I was an active participant, the translated transcripts were read over several times while listening to the tapes; to ensure in the process of translation, nothing was missed out and to fill missing gaps. This was to address technical difficulties of transcribing that Riessman (2008) describes as, a partial representation of speech that might exclude other features, limiting it to lines of texts on a page. Equally a separate native speaker back translated the translated transcripts to check that they were same as the original interview transcript. These processes were all found to be critical steps in the right construction of the exact words as they were meant to be by the speakers.

In the presentation of the research, great attempts has been made to present the research in what Van Maanen refers to as an impressionist tale (Van Maanen, 1988); recounting the events in the order in which they occurred and bringing the text to life as much as possible by concrete details of events as provided by the participants (Elliott, 2005). Furthermore, these events were examined in historical, social and cultural context, to establish the narrative truth and establish coherence (Riessman, 2008). The process of constructions of meaning and the findings were further critically examined with theoretical frameworks for in-depth interpretative accounts. These steps were taken to provide an understanding on where the uncovered truths are situated. Even though the theories adopted were used in illness narratives `developed from western cultures, the deviations that were observed were noted, however some aspects were applicable. Attempts were made to establish the plausible reasons behind the divergence and convergence from the theoretical claims with reference to existing literature. Finally, the research has presented the women as the central figures of the narratives in the world of living as survivors of fistula. To this end, as is typical of

narratives there is no end, the stories do not conclude with a 'happily ever after' outcome. Hyden describes the lack of an ending as a cardinal problem of illness narratives because "they are narratives forever in search of meaning" (Hyden, 1997: 61). In asking women for their final words to conclude their stories, the meaning appears to differ for each woman. For instance, for some it is the continuing negotiation to restore their life back to 'normal'; in the search for a cure or continuing in their responsibilities as a woman that the condition had taken away from them.

7.4 Limitations of Study

Narrative reconstruction is a time consuming sense making retrospective process, as it is not possible to monitor the 'actors' as the events unfold (Czarniawska, 2004). As an historical event, recall biases might have been recorded. To ameliorate this, prompt questions were structured into specific situations to aid recall. Moreover, when women had finished their stories, prompts were used for further elaborations and clarifications. Narratives methodology involves the collection of a large volume of information requiring a clear understanding of context, therefore the ability to identify stories that capture the individual's experience is necessary during analysis (Creswell, 2014). Again, in the creation of core stories, it was difficult to define the boundaries of the stories, judgement was required by the researcher to distinguish what was part of the narrative or not in the interviews (Mishler, 1991). This can limit the meaning the researcher construes of the event. Therefore, to address this in the study, member validation was carried out to seek clarification and elaboration on meanings by reading through the story with all the case studies and some of the participants and asking if it rang true (Emden, 1998).

Using the emplotment method of drawing the stories together under an array of plots is another possible limitation, as the selection of plots can be influenced by the researcher's perspective or interest (Polkinghorne, 1988). Another difficulty is that the emplotment process differs from the typical categorisation by qualitative research as it seeks to give individual story the power to provide "meaningful interpretation of experience" (Polkinghorne, 1988: 168). And there is not a specific standard typology for the selection of plots (Polkinghorne, 1988). In this study, the plots selected were based

on what was considered the peak of the events referred to as the turning point or 'epiphanies'(Creswell, 2014). The narratives developed along the plot lines is a case presentation of a 'composite picture' of individuals rather than individual picture, which can give prominence to some voices and on the other hand silence some (Czarniawska, 2004).

Another of the limitation to the study was language. Even though efforts were taken to ameliorate the interpretative difficulties when translating from native language into English, some meanings might have still been lost out. As not every word in native languages have an English interpretation. The small sample size could be an additional limitation. The study was limited to the experiences of 15 women, which is argued to border on the generalizability of the findings. However, it is equally argued that because narrative analysis is of cases, this does not limit its generalizability, rather inferences can be made on a different level (Elliott, 2005, Riessman, 2008). Therefore, a rich contextual background has been provided to allow for such inferences to be made with the findings.

Even though studies in other countries have linked FGM to obstetric fistula, it is not a cultural practice with tribes in northern Nigeria, hence was not included as part of the study. Moreover, the focus of the study was on experiences of Nigerian women on fistula sustained because of direct childbirth injuries. Again, 'gishiri' cut which is FGC, was not investigated because none of the participant were from the Hausa tribe where it is alleged to be a practice during difficult labour. Consequently, women with FGM or 'gishiri' cut might have had a different experience from the study participants.

The research was a hospital-based study; a community-based study might have been able provide better answer with women in their natural environment. The study site was a repair referral centre. Hence women might be those with more complicated cases, that might have had a more difficult life experiences, although the chances of good mix of participants was also made possible in the choice of the study site.

7.5 Recommendations and Implications

7.5.1 Service Delivery and Policy

Preventing fistula

Strengthening the primary preventive measure on the facility level is recommended. This should involve developing a standard operating procedure/ guideline for child delivery at health facilities; that should include referrals system set up for complications that might develop during childbirth. As noted in the situational report of the unpublished National Strategic Framework to Eliminate Obstetric Fistula 2018-2022, use of partograph is mostly non-existence in most health facilities across the country (FMoH, 2018). It is therefore recommended that health personnel be trained on the use of partograph in birth monitoring. The recently launched National Guideline on Urethral Catheterization for the prevention and conservative treatment of obstetric fistula by the FMoH is applauded as a positive move towards the eradication of fistula in Nigeria (FMoH, 2015a). However, this document since the launch in 2016 is also yet to be published and the need for its urgent implementation cannot be overemphasised. It is therefore suggested that training in the early detection and treatment of obstructed labour (early catheterization protocol) be carried out for health care workers particularly in rural facilities. As a part of this, a prompt referral mechanism to fistula repair centres for unresolved cases after catheterization failed should be put in place.

On the policy makers/government level, addressing health inequities in the Nigeria maternal health service provision should be a matter of top priority. In improving access to maternal health care in rural areas, it is recommended that the government needs to improve funding of maternal health in rural communities. Funds should be provided in building and providing equipment, and staff to health centres with capacity to carry out emergency obstetric care; with steps put in place for motivation of staff to encourage working in rural locations. It is also recommended that the Midwives Special Scheme be re-launched with the strengthened commitments of all stakeholders; government (federal, state and local) and most importantly the community for sustainability of the scheme.

Consideration can be given to the resuscitation of Maternity Waiting Homes in Nigeria that operated successfully as Maternity villages in Eastern Nigeria villages in the 1950s

(Figa'-Talamanca, 1996). It is suggested that further studies be conducted to determine the workable framework for its implementation in modern day Nigeria. Again, one of the major hindrances to utilisation of maternal service in this study was financial constraint hence it is suggested that there is need to consider abolishing user fees. Alternatively, Community Health Insurance program should be rolled out for rural dwellers beyond the current National Health Insurance Scheme that covers workers in the public/government sectors to bridge the gap of health access.

On the community level an improved community partnership in creating awareness on and utilisation of SBA in health facilities is required. It is recommended that community partnership be developed in organising local transport for women to health facilities for child delivery (for instances purchasing specially built bicycle/motorbike ambulances that can navigate the rural terrains). There is a need to partner with community and religious leaders in mobilising enrolment for the Community Health Insurance scheme. Furthermore, upholding the human rights of women and girls needs to be promoted on the community level. There is a continued need to keep promoting girl child education, exposing the dangers of early marriage and promoting the use of family planning methods. It is recommended that the current efforts to promote the rights of women and girls through education and reproductive health through partnering with community leaders be intensified for a more productive effect in achieving Universal Health Coverage.

Treatment of Fistula

The establishment of additional National Fistula repair centres is a laudable objective to improving access to care, but the services remain inadequate as noted in the strategic framework report (FMoH, 2018). On the secondary prevention intervention at facility level, the training of more dedicated fistula surgeons and nurses in the treatment is recommended to clear up the backlog of cases and meet up with the newly developing cases. On the government level, a sustained support and improved funding of fistula repair centres is recommended. It is equally recommended that increased funds be allocated for full implementation of comprehensive rehabilitation program that includes

IGA in management of fistula beyond policy document. This should include provision of equipment and staff for rehabilitation centres.

Equally important for successful treatment, is community mobilisation and involvement for creating awareness on the availability of fistula treatment. This mobilisation is also recommended for the prevention of stigma in the community that might hinder women coming out to seek treatment. The mobilisation should involve partnering with community and religious leaders to generate support for identifying women that require repairs.

7.5.2 Further Research

The sexual and reproductive health issues remain a concern with fistula survivors; further research on how this can be addressed is suggested, based on the contextual importance of child bearing to women in the society. Another issue to be investigated is SBAs whose identities were unknown, undertaking home deliveries. The evidence of sharp practices as observed in the study is believed could further complicate issues of the preference of home deliveries that contribute to maternal health issues. The research suggests that early marriage is not a major issue, rather a shift in the demographics to include older women not reported in northern studies. Could this change in trend become a healthy development for campaigners against early marriages or another strong indicator of poor health care system in Northern Nigeria? Further research is required to assess this. Finally, not every woman could utilise the income generating skills acquired. There is need to address the one cap fits all approach to rehab; research is suggested to determine how rehabilitation that involves skills provision should be organised and skills that will be useful to the environment women come from for sustainability.

7.6 Conclusion to Chapter

The final chapter of the thesis summarised the findings of the study. In drawing a conclusion, a brief discussion was also provided on the role of author's reflexivity in conducting the research. The contribution to knowledge of the findings were also presented and the limitations that were observed. In this final chapter, the implications

and recommendations of these findings for practice, policy and further research were outlined.

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APPENDIX 1 CORE STORY CREATION

Appendix 1a - Story one: Halima

I am from Minjibir Local Government. I was given out in marriage at the age of 14., after I got married I gave birth when I was 15 but before I gave birth... I was in labour for 3 days. I used to see a doctor before then and the doctor told me that the child was too big and that I need to be taken to the hospital when it is time for me to deliver. But because we have our culture like that of the Fulanis, my parents came and took me from the town where we were staying with my husband to the village that it is not good for me to deliver alone because I was alone with my husband at that time. So, I was taken to the village. I still remember what they told me at the Antenatal Clinic that when it is time to deliver I should go to the hospital. I didn't tell them that until I went into labour, that was when I told them that the doctor had told me that the child is too big so when I start labour I should go back home so that I will be taken to the hospital, that I should not agree to anyone making me give birth at home. My late grandmother (May God bless her soul) ... said "look at you!!...There are smaller girls than you who have given birth at home and you are hoping that you will be taken to the hospital!" I told her that it was what the doctor said, and she said I should shut up. I started labour on Tuesday; I did not give birth and went through Wednesday. My mother was not home when I started labour on Tuesday and went through Wednesday. She had gone for a wedding. And it was when she came that Wednesday she insisted that I be taken to a hospital...

Our village is off the road, there is only one vehicle in the village. They went to get the vehicle but were told that he has gone out with passengers that we should wait for him to him to return. He did not come back until around 9:30 PM. That is when they took me to the clinic... But the clinic in our village was very small. From there, they told us that I cannot give birth there, that I should be taken to a bigger hospital in Kano city. I was taken there on Thursday and I spent the night there up until the early hours of Friday. Initially, they said they were going to operate but because we don't have money at hand and they said they will not touch me until I pay, the surgery was not done. One

of the doctors said since they are not going to operate, they should at least try to remove the child because the child as of that time was already dead. So, one woman climbs on top of me and was pushing and squeezing, while the doctor had his hand in my private part and the two of them were struggling to remove the baby. At last they succeeded in removing the baby by force.... forcing the baby out, his body was already looking decomposed...was looking decomposed. It was after removing him by force that they transferred me from that room to another room. They put a catheter on me and I was there for about five days. After the five days they said the catheter should be removed so that we will be discharged. They removed the catheter and discharged us. We went back home. I was lying down, when I made an attempt to sit up, I heard something pouring out. My beddings will get wet and my mother will change them. We kept wondering what was happening. When some women came to see me, my mother explained the situation to them and one of them said, "I hope it is not urine". To be honest with you, I have never heard of urine leakage before that time and my mother never knew what urine leakage (VVF) is so she asked, "How can urine leak?" When they noticed that my mother is beginning to panic, they suggested that I should be taken back to the hospital where I delivered. When they took me back to the hospital, the staff said I have urine leakage and the long labour that they made me have at home was the cause of it. They suggested that we come back on Sunday to see the doctor. I was brought back on Sunday and the doctor saw me. The senior doctor was not around so the junior doctor told me that he has examined me and that I should be patient as he cannot do anything about my situation until the senior doctor returns. I cannot forget, as at that time, anytime I squat, something will bulge out from my private part. If I stand up, they will have to press and close my legs together before it will go back in. I honestly don't know what that thing is. We went back home and stayed until the senior doctor returned, he was on leave...I stayed at home for about one month before coming back to the hospital he operated on me the first time, it didn't stop, worked on me the second time, it failed; they did the third surgery but honestly... I still wasn't healed, I was still leaking urine. He did the fourth surgery and I still wasn't any better. The same doctor did all those surgeries, so we began to think of changing to another hospital. Some were suggesting Katsina, some were suggesting Jos. We discussed our options and decided to come to Jos I will not forget in the year 2000. We came to Jos... In Jos, when the

doctor examined me, he said that at that time, where my urine pass (urethra) is tired and so he will not be able to do anything unless reversal, but I said I don't want that, but a white female doctor came and said she is going to give it a trial. She did, and the leakage reduced significantly so they gave me time to go and come back. When I came back, I was linked to another visiting doctor (I don't know where he came from), he operated on me making it six surgeries...the sixth surgery. I didn't have another surgery after that, I was just living like that until much later that I heard about another type of surgery that produces result.

Before then, I will take you back.... when I was staying after that last surgery, I was able to join the rehabilitation centre here where I was able to learn a trade. I met women, some learning sewing, some learning knitting and it was all free, none of them was paying anything so I decided to join them; I joined them and in 2003 I learned knitting. After learning to knit, I went back home, and God helped me, I was knitting things and selling them and later some people came and hire me to teach knitting on part-time basis. It was during that time that I heard about another surgery that produces result, so I came back last November (2015) and he operated on me, but I developed complications after the surgery. My stomach swelled up and I developed fever that nine days after that surgery, I was taken back to the theatre where I had another surgery, which resulted to the spoilage of the former surgery. So up till now, I am still leaking urine and now I am back, and they said there is nothing left that can be done except that diversion which I don't want. I am praying that God will bring another technique that will come later, which will help us come out of this urine leakage...I have now lived for 22 years with this problem but I am thankful to God because the leakage has not stopped me from carrying out the trade that I learned which even though it is not on a large scale, but it has helped in meeting my daily needs. We have nothing to say to Jankwano but to thank them, praying that God will reward them and that God will increase their wisdom...for all they have done for me...

Honestly...I have gone through many ups and downs though I am thankful to God because it has not separated me from my husband, we are still together but I have

experienced different challenges especially from his relations and others. I honestly have to say that I did experienced many changes and challenges that sometimes will make me cry and sometimes when I begin to think of it, it even prevents me from sleeping. The way they (in laws) show hatred, stigma and discrimination to me, is as if I used my money to buy it or as if I am enjoying what has happened to me. If they hear that I have gone to the hospital, some of them will think I am just roaming about not looking for treatment, some will be saying why can't I be patient and stay like that, but it is only me that knows the thing that is disturbing me. If this leaking will reduce to the very minimal, I can be patient and live with it, but I am still leaking even when I am lying down on bed. You can see that I still have a problem. A grown-up woman like me, and not a baby waking up in wet rags every day is really a problem. That is why anywhere you heard there is possibility of getting help, you have to rush there... but some people sees it as if I am just enjoying roaming about that I am not seeking for treatment...they think I am just leisurely roaming around... Even during my last admission, my husband's relations sent some people to come and investigate if I am really here and whether I have truly had the operation, or I am just sitting down here. I just saw them appear without them notifying me that they are coming to see me.... Yes, when I was on admission here. When they came they met me on admission I used to be fat, they found me very lean and black. That was when they realized that I was really suffering. This is really a big challenge to me, but God is there... Yes, I faced challenges as a woman that no one should face, because of my condition my husband married another wife, so I have a co-wife... Like I told you earlier, I have challenges...There was a time that I cannot forget. It was during the cold season. When she wakes up in the morning she will wash her hands and legs and rub cream but will not bath. So, this morning our husband went in and met her washing her legs, so he confronted her on why she will always wash her legs and refuse to take a bath. If you heat up water, you will should be able to take a bath...Nothing should stop you. The words that came out from her mouth was, "the one that bath every day does so because it has become a most for her to bath let her not bath for one day and see if she can interact with people." You see!... Some will treat you normally but some, you will be interacting normally together but the moment you turn your back, they will turn to look where you were sitting whether it is wet or to look at your back. If you sit for too long, even you yourself will be afraid of standing up

especially if you are among people. Because of things like that, you will have to be avoiding people. Because the thing had lingered for too long, definitely you must know how to take care of it since you have had it for years, it is not for one year or two or ten but many years... it is with you always. So definitely I have to find a way. Before I could reach the stage of knowing how to handle it, I was finding it difficult to associate with people. But in those initial times, I didn't know how to handle myself to be able to go where people where... As a woman... honestly!... there was a surgery I had that I couldn't forget. I had the catheter on, when they removed the catheter and I saw urine coming out, I went to the gate and sat down, there is a well near the gate. Because of how bad I was feeling at that time, I began to think of throwing myself into the well, so they will look for me and not find me. Here was I sitting close to the well... Anytime you have the surgery, you come out with the hope that that will be the end of it but up to now, I am still hopeful that by God's grace, I will be healed... As a woman... truly I am very worried as a result of lack of children. My co-wife has children, she has three, and I don't even have one... Barrenness is not a small disease to women because you will also want to see your own even if it is only one but see me here, apart from that first one, it is now 22 years I have not given birth again. I have had miscarriages about five times, but each pregnancy has never passed three months...two months and it comes out by the third... These are the problems I am facing...

I honestly don't have any problem with my husband because he treats me the best way he knows how to, so all I can say is "may God reward and bless him and may the Lord encourage him as he continues to look after me" ...yes we do relate (sex) ...Well I once faced a problem after the first surgery I had. They closed the place so there was no menstruation, no sexual intercourse but when I came to this place, I met one Dr Km and after one surgery, that problem was solved...but now over the years...he has stopped coming like before.... He remarried because of this problem like I said. He married when I was in the hospital, but despite that marriage, he didn't abandon me, we are still together even though he is married...I did not know about the wedding, honestly, he didn't tell me, I only heard about it later... he told my mother but told her not to tell me because of the condition I was in and I should not be told so that it will not upset me the more. So, it was much later that I learned that he is married...Honestly, at that time I

was told he was married, at that time I was on admission in the hospital...honestly, I really felt hurt and bitter at that time, and I cried...I cried seriously...because of hearing about his marriage... “So why will he hide it from me...why will he tell them not to tell me”, I really felt hurt...Particularly because he told my mother not to tell me... “Why will he say they should not tell me” ...honestly, I cannot forget this... It became a problem for me for I cried seriously at that time ...honestly, I cannot forget...honestly... I was wondering why he can't be patient for me to get better, come back and get back to my room... He now said they should not tell me...he told my mother not to tell me...And I know he never wanted my mother to hear about the marriage, but he knew that there was no way it can be hidden that my mother will not hear about it. So, he had no choice but to tell her, so he told her not to tell me... after my mother was told, she became disturbed, she was always crying. It took a while for me to get it out of her...I kept disturbing her with questions... “What has happened? What has happened at home” ... she now said “see, see... your husband has married, and he said I should not tell you” so that is why I am disturbed. After that I started crying and felt hurt that it became a problem that affected me seriously. Honestly, I felt hurt wondering “Why will he not tell me”, why can he not come and tell me” even though there is nothing I can do about it. And even after I had heard, he never came to see me even though I was still on admission...honestly, not even once did he ever come to visit me all the times I was on admission in the hospital... For the past 15 years I have been coming here for treatment...honestly...he has never sent any money for my support all these years...honestly not even a penny has he ever given...as for my relationship with my husband at home, I have only one desire now, I pray that God will help me by providing another way of treating this urine problem because now I just feel as if he is just patching up or managing with me, I just have to bear it... honestly, he allowed me to come because of this swelling in my stomach(showed the swelling)... left for him, I should accept my fate and live with the urine leakage... but how can I? I want to live a normal life and be free of this urine and I remain hopeful one day I will be rid of it by God's grace.

Relationship with healthy friends has ceased, honestly my friends now are those with similar problem like me. Honestly, I am no longer friends with friends that are healthy,

honestly, I will not hide it from you...my friends...all my friends are those with leaking urine... people with my sickness. Why, because when I go among them I am not comfortable...you know there are different kinds of people... some will show you love...while others because you have this sickness will stigmatize you... you touch even a plate, you will notice they do not want to touch that plate to use it...so that is why I stopped being friends with my healthy friends like I used to when I was healthy and my friends are those that are like me in the same condition. We relate together, and I visit them, they visit me, most especially though that we are always together in the hospital. As you would have noticed how we relate with one another here

My parents! My dad is already dead and from my mother's side, she has only one sister, so we don't have a lot of relations, but the relationship is still very strong...but honestly it is only once my mother was here with me, I suffered a complication and I didn't even know where I was at that time... I had a serious complication and so they said they had to look for a relation of my husband or my mother that must come. At that time, my husband's relatives did not come and so they called my mother on the phone so that is why she came to check me. And when I got well, she left for home. And so most of the time I was coming here alone, so among ourselves...among ourselves... those of us in the leaking urine "group" normally assist one another. If you have been given a long time to wait for your repair, you will help to care for those on the bed. And this one, if you are better you help to care for another...that is how we do it helping one another and that is how it was with me. But because I had this complication it became compulsory for my relation to come and so they called her... it was compulsory for her because they called her...

Everybody in the neighbourhood knows about my problem especially because of the co-wife. Even the one that did not know now knows. However, I am not accustomed to entering people's homes and it is only when you go there that they will have the opportunity to treat you badly.... Honestly, I cannot go out into the neighbourhood or visit my relations to sit with them and socialize with them...it is because of the way my co-wife has spread stories about my ill health...for instance when I come to the

hospital... we do not stay in the same house, we live separately... but she meets with women she will tell them to be praying for I have gone back to the hospital. There was even a time when I went back from here, just by the roadside a woman stopped me saying "aya" (oh my), are you back? How are you doing? May God help you this time around and you succeed"!! How did she hear? I don't enter their houses and I never told anyone I was going to the hospital... so how did she hear... is it not my co-wife spreading stories about me to everyone? Someone told me she is the one telling everyone of my condition. Honestly, this issue is hurting me seriously...and I am not happy at all...Honestly, life is not sweet... one has to just bear it. You just have to be patient. I am just 'managing' life... Whoever is in this kind of state can only be patient... There is nothing you can do...it is just 'manage'... yes, it is 'manage', what else? I am 'managing' life

Honestly, it is a big challenge, because of the way my own urine is leaking seriously, I cannot go out to where people are. But since I have lived with this urine for such a long time, I have learnt ways in handling the urine. It has become compulsory for me to learn how to handle the urine, so this has helped me to enter where people are. However, I am living in an unbearable condition...honestly, I am in an unbearable condition, that I can never forget my condition. Even as I talk with you now, that is the state in which I am... with the urine, I have had repairs but up till now even though it is better, but as God wills the urine is still leaking. But I am still hopeful and praying that one-day God will help the doctors to have a way or wisdom for them to address my issue by God's grace. Because, as for me I have not given up hope that I will be cured... I have not lost hope, everything has its time, and I know by the grace of God I will be cured... because we are in serious predicament, those of us that are leaking urine even if it is just for one day you know how it is talk less of for me... That each time I lie down it is leaking. Honestly sometimes, if I sit down it can gather...but as soon as I get up before I get to the toilet it has started leaking out down my legs. This is really a big problem...

In order to manage the urine leakage, initially it was difficult because I didn't know how to manage it, you know it is not like menstruation that will flow for a while, this is

something that flows none stop so you have to know how to manage it especially since you don't have the resources to be buying things like pampers and even if you have the money, doing this on daily basis will run you down, 22 years is not a joke. I got an idea of going to the second-hand clothes dealers to buy towel that I will bring home and cut to pieces that I will be using as I wash them. If they get worn out, I throw them away and my relations use to bring their old dresses especially those that are soft to see if I can use them and if they bring them, I use to be happy!! With them more than if you give me a new wrapper because no matter how expensive the wrapper is, I cannot wear it and go out without that rag underneath... As long as you are keeping them clean, you are not just keeping them... you wash them and dry them well and again when you are going to use it, you apply a little Vaseline by the sides, you will not have a problem. But if you do not take care of it.... I have heard of many people that have had rashes but as for me, honestly, I have had those rashes when I was using the rags but since I learned how to clean up and use them properly, I have since forgotten the last time I saw a rash on my body. If I am going somewhere, there are different tricks that I employ. You can even spent the night somewhere but mostly not more than one night because for me, no matter where I go, if I spent more than one day, my mind will not be at ease, I get very upset because you will not be able to get a place where you can dry your rags properly and if you use it before it is properly dried, that will be another problem and if you fold it and keep it in the bag when it is wet, that is also another problem that is why I don't spend more than one night wherever I go. Some of my relations were seeing it as if I don't like visiting people but those that understood my predicament don't bother themselves about my lack spending nights in their homes. If is an occasion that is just for the day, I will go and spend my day there and return home...during rainy season since sometimes it will rain all day that is why we have to make provisions, gather as many as we can so that before a certain set dries up, you have some sets you can use when the sun comes out, you dry the wet ones

At the time I came, there was that lady that was teaching them as I was living here and doing nothing for three months, I said to myself, I better join this people and learn something. Yes, that was when I joined rehabilitation centre when I was doing my bladder training and we learned a lot. Although I am not into it on a larger scale,

honestly, I thank God for what I am able to achieve through it. I learned knitting, making pomade and the rest of them. I didn't learn sewing. The truth is, throughout my stay here, none of my relations came, close to four months I stayed here nobody came ...even my husband, honestly, he didn't come too...Let me tell you this... (Swearing by Allah's name) ... He didn't send money or nothing... I actually wasn't happy, apart from those in-laws of mine that came, and their visit wasn't meant for good since what they were supposed to have done was to call me and find out how I was doing and then inform me that they are intending to come to visit me but none of that happened. They didn't call me, I just saw them dropped in... And I know how our relationship has been like at the time, the way they were stigmatizing me and so on... My hopes were to see that I am healed and that those that were stigmatizing me because of my challenge will receive me with open arms... and not behave badly towards me as they use to do. I left here with the intention that someone will learn from me what I was able to learn from here and I was able to succeed in that because I was able to train some people that are now using it as a trade, I am very happy and I thank God... we had freedom ceremony. It helped in making the program elegant and we had a good time during the occasion. The people that were responsible for training us, the invited guests and the dignitaries all came together in a celebration mood without stigmatizing us. We celebrated in a joyful mood, we had our uniform and all. After finishing with Jankwano, I went back to my parent's house... I didn't return to my husband's house because at that time, there was a problem... At that time, we were living in the same house with my co-wife and the life wasn't pleasant, there was jesting, mockery and the rest. That was before he got me my own house. Initially we were living together... we started having problem... she started asking him for a divorce or he should get us separate houses, because she cannot live with me. So, he rented another place for her and that is why we live separately...before we were together... is because of the urine... because of the urine...because of my condition and we are living in the same house...honestly, you know we are stigmatise. A lot of people stigmatise us...It is only in the hospital here we do not experience that stigmatization. If we come here, we do not experience it.... here we feel relief and can enjoy ourselves, because of the way they treat us. That is why I do not have anything to say but to appreciate Jankwano and pray that God will bless them and make the hospital to become greater. This is my prayer today and even tomorrow,

and always...that God will take the hospital higher. Do you know why? When we come here, "by Allah" the way we enjoy, cannot be compared with what happens in our homes with our parents or with our men...honestly each time I am leaving my house to come to the hospital, the way I rejoice within me is as if I am going to visit my relations. And when I have to return home, I have bad feelings within me and I am so sad. Why? I am going home and yet I am unhappy...and I cannot enjoy myself... but if I am to come here... I am counting days to when I can come... because I can be myself. Oh! I want to be free and enjoy my life... we (co-wife and herself) live in different houses...our husband visits... we share the days in the week and he alternate staying with each of us... that is how we share it. I stayed for about one year before the houses were divided. Initially the thing started as if it will not be possible but later, everything worked out...it has reduced because I have where I stay, no matter how troublesome she is, she will not be able to do much unless I go to where she is...

I honestly wasn't happy when I had to go back to my parent's after treatment because no matter how much you enjoy your parent's house, living in your husband's house is better but because of the problem on ground, I couldn't do anything but to bear with the situation... I went back home still leaking urine after spending months in the hospital. ...That is why some people were saying I wasn't coming to the hospital because the way I left home leaking urine is the same way I will come back leaking urine, but everything has its time, God has not brought the time for my healing yet, but I am still hopeful...

Pleasant?... honestly it wasn't pleasant, that was just how it was, and I had no option. A times, I even will even be thinking that it might have been better if I had remained in the hospital instead of coming back home because a times, staying in the hospital is more peaceful that staying at home... Because in this place, you come across many people with similar problem and there is no discrimination or stigmatization but at home, the moment you stand up, they will be looking at where you sat, the moment you turn your back, they will be looking at your back to see if the urine is running down your legs. None of that will happen here in the hospital even if you are the only one with it...

There were people who contributed like my parents and my relations, that was at our first visit...now I come on my own. For close to 20 years now, I have been running around on my own. There is tiredness, unless like I told you earlier this time around when I ran into a very difficult time that they had to get in touch with my relations, they called my mother on phone who later came to join me here. Apart from that, I have been staying in the hospital alone all through my surgeries. Too many surgeries, tiredness and lack of resources all contributed to that. Sometimes even raising the transport money is difficult but we thank God. As for my neighbours in regard to my problem? What is their business? I have been to the hospital and I am now back and still leaking urine. Some will even come to see you, but they are really not coming in to greet but in reality, they are just coming to access if you are healed or not. Especially immediately after you return, they will come and fill your room and refuse to leave. All they want is for you to stand up, so they will see how things are, so they will go out saying, "She came back with her urine as usual, and she has not been healed." They did not help me in any way...everything has its time...None... honestly none...

In the rehab centre...in the rehab centre...the first thing is that once you are in that place, you forget about your problems, your thoughts are no longer on your condition because you are all together, many of you and you are happy together while you have great hopes that the thing you are learning will help you in the future. Even that is something to be excited about...again the thing you learned was helpful... I have told you that earlier, (laughed) I have become a trainer that has trained others who are now good at it and they do it and sell to make a living. And I am making something that I can use to buy detergent to wash my things, buy other things out of it. I am no longer depending on my husband, if he is able to provide, fine; if not, I use what I was able to make... honestly there are... I would not on my own have been able to do what I am doing now... helping to train others and even selling some of my products if I did not have the training here. The training helped to give me the exposure to relate to people. I am learning not to pity myself, but keep going out in spite of everything...

My fears...uhmmmm... I fear been sent out of my matrimonial home, honestly, I fear him (husband) dying before me or reaching a point where he will say he is tired. If I remember these things, honestly, I become very restless and disturbed... Honestly... these two things, him dying before me or him getting tired of me. If any of these things happen, what will I do with myself... because I have seen women that were divorced even as they are lying down on hospital beds, I have seen those that were divorced at the peak of the problem and when they got better, they were able to remarry but the marriage did not last. Am I going to be a victim of that? If I think about these things, honestly...it disturbs me a lot... not in a small way... but oh! If I am cure and I go back home, you know it's because of the urine problem I am been brought low and those stigmatising me have stigmatised and even discriminated against me, even though you are making every effort to get a cure.... I am hoping by God's grace that everything will become fine... I am hopeful that God will make that time possible that I will be cured...

The only thing I will like to add is that the only thing that caused all these problems is just one thing and that is what my parents did to me. I was attending antenatal clinic, but my parents took me away from the town to the village because of tradition or customs of 'nursing a newly delivered mother'... The doctor had already told me that the child is too big that it will be best if I deliver in the hospital, he said that because he had seen something and I told them but they rejected that, that because I married inside town I have the mouth to tell them what to do and how to do their things. Saying what happened to my younger ones that have delivered in the village? They have forgotten that our bodies are different. The doctor must have his reasons for saying what he said. They did not think of that, but I left me to spend all those days suffering in labour up to the point that the child got decomposed inside my womb. I will beg our parents to always listen and do what the doctor says. If pregnancy occurs, the husband and parents should not stop their daughter from going to the hospital where her health and that of her baby will be checked. They should stop all those traditions...That is what is responsible for all the difficulties I have gone, and I am still going through. That is what I have to close with. My plea is that people should visit hospitals so that doctors will advise appropriately; they should also not allow women to go into labour at home

because it is not good. That long labour is what is responsible for my problems...That is all I have to say in closing.

PS. (debriefing session) - Upon reading through the story to confirm the story, Halima added:

"I told you I had seven repairs, honestly, they are up to 14, you count...in Kano... (Mentioned names of doctors and repairs) how many is that? In Jankwano (mentioned names of doctors and repairs) ...is it not altogether 14? Is it not?". "If I tell people 14, how will they look at me, wouldn't they think there is 'something' wrong with me...? What do you want me to say...? I have to say that, so people don't look at me anyhow...what can I do?" ... just so, I say 7...I tell them 7, yes that one is even bad enough... 7 but it is better than saying 14..."

Appendix 1b – Story two: Margaret's story

Current continence status- dry

I am from Kargarko in Kaduna state. I got pregnant when I was 18 and was taken to the house of the man that impregnated me, when I was five months pregnant. During the pregnancy, no problem...only I had dysentery one time during the early months... I was vomiting and passing stool with blood. After that one, nothing again... I was in labour for two days at home, there was no plan to take me to the hospital because of money issue anyway. I didn't even register for ANC until very late (one month) because of the money issue. At the ANC, I was told my blood was short, I was advised to eat vegetables that is all. So, when it started, it was in the night... I was just there with my mother in law...it was one of my husband's uncle that came from the town that said, "You need to take this girl to the hospital". It was then I was taken, I gave birth and then I started leaking urine... I gave birth... I don't know what happened, but as I was sitting down

after delivery, I notice something just dripping from me and I wasn't feeling like urinating. We were in this hospital for one week and I couldn't walk. They put catheter into me. The nurse there after some days removed the catheter and I was dripping urine. I asked my mother what was happening because I didn't understand it. She said she was going to talk with the doctor. The doctor said he doesn't understand it either, he told us that he has done his best and he doesn't know what the problem now is. So, mother asked him what we should do. His response was he has done his best the only thing he can do is to discharge us to go home. I could not walk very well... My mother said its ok, so we were discharged. We later went to a prayer man, who advised I should be taken to a hospital. We now went to another hospital and while they were checking me, they found they had left cotton wool in my private part and it was removed. This cotton wool was inside me for one week... He now mixed what I later discovered to be Izal, which we use to mop the floor when I started working here. He would add the Izal with Dettol and this he was using to clean my private part. It was giving me much pains. When he comes to do the washing, if I was lying down, I cannot stand up again, except to remain laid down, to sit down was torture. If I stand up, to sit was problem and even to lie again was torture, I would feel as if something was 'soaking' me like cotton wool inside. I could not walk well with them. And I was feeling serious pains in my private part. Each time he comes to pour the mixture into my private part it was making the pains worse. He was doing this twice a day, morning and evening, he would do it in the morning and at night before I sleep, this was what he was doing always... when we had spent up to 3 weeks my father felt I was getting worse, so he asked him to discharge us. The father of the baby felt we should go back to where I did my antenatal. Since it was there they started giving me some medicines, maybe they will know what to do. So, we went back there, the man now asked me to lie down and as he was about fixing a catheter, he put his hand into my private part and he brought out a cotton that had been in my private part for the past three weeks! He then removed the cotton wool...after the doctor removed it, he was asking me where it was fixed. The way he was talking, it was as if he was going to do something about it. I told my father that the doctor had removed cotton wool from my private part and was questioning me. You know in the village how things are, my father was afraid and did not want any trouble, so he said,

and we are the ones that went there so the doctor should not bother about it. He was afraid that doctor was going to make trouble...

The first time we were there my mother had “asked you don’t give her injections or drips, what kind of sickness is this”. The man told her “this kind of sickness you don’t give injections or drips”. For the one month we were there he never gave me any medicine to drink only to wash my private part, he even fixed a catheter, but the urine was not going out through the catheter. As soon he removed the cotton wool, I could walk better. My mother was surprised that I could walk. He told us he has done all he could for me and in fact he fixed something that looks like a syringe in my private part that could be taken off, so that the urine would pass through if I wanted to urinate, I could open it. But the urine was not even passing through the thing. He wanted me to go home with it, but I refused and asked him to remove it because I could not do it, but I would put rags. So, he removed it... I was using rags. The clinic staff, called my mother aside and told her that they have heard of a disease called VVF but they don’t treat it in that clinic unless we go to Jos and there was crisis in Jos around that time so they said the only advice they can give us is to wait until after December before we take the trip to Jos. For three months I was home...I could not go out where people were.... if I sit down like this... if I sit down...the urine would be leaking seriously... again they stopped me from drinking water, saying I should not drink water... I faced many challenges although I had the support of my parents. I could not sit among people or even go close to people. If I go close to people, they all will one by one leave the place. You don’t have to ask why, you already know it is because of the problem you have, because people will not like to come close to you. If not for you workers that are coming close to us, nobody can sit close to you. Even getting soap, sometimes if my mother is angry, she will say, “Where can I get the money?” Sometimes I will just pack my clothes and wash them with water and dry them like that, no soap. At that time, I returned home after being discharged from the hospital. When I lie down, I felt pain in my abdomen; also, urine would be rushing it out. With the urine that was rushing out, I felt my private part very itchy and I develop boils and rashes. I felt pain in my private part because of the things (rags) I was using to catch the urine flowing out...The rags were causing me pains...they made me feel much pain. Sometimes, I had headaches.

As I sit, I was always thinking because of the urine I could not go out where people where. I was always thinking...how my life has changed from how it used to be... How I can no longer stay in the company of people. How my life will end up since I did not know what this sickness was and if I would ever get well again...It was impossible to sit with people. If I sit with people immediately they would begin to move away, because of the smell of the urine. If I drink water, immediately you see the urine pouring out...when people moved away from me...I felt pain in my heart... why is this urine coming out I ask myself... People were saying they have never seen this type of sickness others were saying it was water from the inside. But I was saying I do not feel any urge to urinate, yet the urine was coming out. Some people now advised me to stop drinking water, so I stopped, but I will be feeling so thirsty. Even though I stopped drinking water, the urine was still rushing out...

Finally, after December, we came to Jos and we were told that there is a place called Jankwano that does that work and they do eat for free and they even feed their patients. My mother said, "In this era when everyone is looking for money, how can somebody treat you and even give you food for free"? My father said what we are going to do is we will hold some money if it is true that they don't collect money, the money will not be a waste, but we need to come with it. Somebody brought us in a car, when we came in, we collected a card and did a number of tests after which we were brought to the VVF centre. A day for surgery was given to us, which my surgery will be done after three weeks. We waited for three weeks, after which I was admitted. From there they took us to the laboratory for some tests. The tests were done on a Wednesday and I had my surgery on a Thursday. I was taken to the theatre. I didn't feel as if they were touching me. When they were done, I was taken back to the ward. The place they injected me on the back begin to pain. When I wanted to turn, they said I cannot turn. Some of the women that came out from the theatre started complaining of stomach ache, some were very restless and uncomfortable, but as for me, it was only the place of injection that was paining. I wasn't feeling anything on my body. If my mother comes around, she will touch the bed to see if it is wet, but there was nothing because the urine is going out through the catheter. I asked for water but was told that I cannot take water until the next day. That night passed. They woke us up in the morning around 4am for

morning prayers; I came down from the bed and started walking. My mother ran to the nurse and asked her that her, "My daughter is walking, have they really done any operation on her?" The nurse told her not to worry but to be thankful. "See your daughter is able to come down and walk on her own." When I came down, I thank God, but my mother said, "I don't believe they have operated on this girl, how comes she has catheter." Because the hospital we went to told us that women who have VVF don't take injections or use catheter. When they came to inject me, my mother went out crying saying may be her daughter is going to die. When she got herself together, she said she will wait and see what is going to happen. She saw me brought back from the theatre with IV fluid, she kept touching me. She checked my stomach, she didn't see any cut. She went to one of the nurses who is the same tribe with us and was asking her whether I really have had surgery. She was asking, "What type of surgery is that? This girl has not had any surgery. See, her bed is not wet." The nurse assured her that it was because of the surgery that was why my bed was dry. I started taking water and took a lot of it. Some women were complaining that they don't feel like taking water, but for me, I was just feeling like drinking water because when I was leaking urine, I tried to avoid drinking water because it kept coming out. I don't know when the urine will leak out. After four days, the catheter was removed. Every minute I will go and urinate, I don't even wait for my bladder to be full. My mother started complaining about my frequent urine. But I was able to go and pass urine by myself. Later, she started encouraging me. On Sunday, the doctor came and looked at us. I was taking a lot of water, so my container kept filling up. My mother was throwing away urine every minute. I wasn't feeling anything except the water I kept drinking. As I was drinking water, some whitish thing came out along with the urine, I kept telling myself that it might be accumulated dirt. It kept coming out. When it stopped, I was discharged. So, when I heard that I was going home...On that day, I felt like I was just coming down from heaven. It was like a dream. As I sat down, I kept touching myself thinking, "So now I can urinate by myself, I have been discharged." I cannot express my joy. It was my grandfather, that I saw first when I got back home...I was very excited, so excited that I began to cry. He started crying and I joined him. I kept talking about it at home. "So now I can urinate by myself, I have been discharged." My sister was asking, "what kind of celebration can we organize for this girl, that is standing here dry, no bed wetting, what

are we going to do to celebrate with her?" I told her of a song we were taught that says, (started singing) "leakage has stopped, no more worries, only thanks giving to God". When we went to church, I sang the same song. The pastor of our church, who was the only person that was able to constantly visit my mother so that she will not be overtaken by grief, said, he doesn't know how to appreciate God for what he has done on behalf of this girl. I said, I am also short of words to thank God with. The women fellowship members were very excited, they use to help fetch water for my mother during my illness. It took one week before I was accepted; some were saying maybe they just gave her 'something' to stop the flow of urine. It is not that they cut my abdomen or there are any stitches on my abdomen to show they did a repair on me. If I had had an operation I will not be doing the chores I am doing. I was doing chores in the house, so they could not believe I had undergone an operation. They also said if I had undergone an operation, I would be going frequently to pass urine; I will not leave the urine. But this was not the case. But I have forgiven them for all they said. It took me sometime to really be free. About two months, after that I even started going for communal farming.

After my discharge, it was like... I took a long journey, now I am back into new life. I am happy with my new life, sometimes I tell the women having this problem as most of them never knew that I have had the experience that they should not worry, they too will one day be like me. Urine leakage will go if you trust in God and leave everything to him. Don't bother about the way people laugh at you today or because of the poverty you are going through. Sometimes you even think that things will never be normal again, but you need to leave everything to God. Sometimes if I see them crying, I use to cry along with them. Sometimes I do forget that I have had that problem... my parents... my parents have helped with advice on day-to-day living. They showed me that I should not take my getting well for granted and go wayward. They advise that I should live a life that will please God. I shouldn't turn my back to God instead, I should appreciate him. They advise me on the Word of God. My present life compared to the life is better than the former one...It is better than before. Even though I was in school before coming here, I don't know how to speak English, I couldn't read well. But now I can read, I can spell words. I am helping myself so that if God allows me to marry, I can help my children...I am now going to school and working. I go out each day and I meet people.

Instead of sitting at home and pitying myself that I have had VVF. I have decided to let go of the past and face my studies and my work to make my life better. Like in my working place, the staffs help in teaching me to read. They are helping me with my studies.

We went back home where I stayed for three months. The day I was discharged, we were told that there is a training centre where one can learn things like sewing, tailoring, and other handcrafts. People that are interested can go home and come back later. You don't have to pay anything as that too is free. I went to Mrs S and got myself registered without the knowledge of my mother. When my mother heard of the training, she said she doesn't want any sadder news. But she asked me if I think I can do it. I told her I will come back. My father said, how can you go and learn a trade in town where you don't know anybody, you don't have anybody that can take care of you. They said they will have no part in that. I assured them that I will come. I came back, expecting myself to be turned down, but I was accepted. We started learning how to sew, we will go and collect food just the way we use to do as patients. We were given food, soap, everything. Sometimes visitors will come and share gift items to us. Sometimes the workers will give us gifts including that of wrappers, dresses and different stuff. I don't have a phone at that time but one day I called my sister at home. She said she has been hearing of the crisis in Jos, that If I think I cannot stay, I can just go back home. I told her not to worry, I am as comfortable in this hospital as I was at home. We were very well cared for. I wasn't thinking of who will take care of me because we were all properly taken care of. Even though you cannot compare any woman with your mother, but I was enjoying my stay here. I went home for Christmas, after Christmas, I came back. A time came when we graduated because I learnt sewing, knitting, I can prepare pomade, I can bake cake, and I can make chin chin (snack), and so on. At one time, we were taught how to make ear rings that at one time, a group of women gave us a contract to make ear rings for them to use at their sing song program. We can make earrings and different other crafts. Sometimes when the woman in charge is going to cook, she will invite and say, "Come and learn how they cook in the town, who knows if you will end up marrying in the city." We will go and learn. They have taught us a lot of things. It was after the

training that God opened door for me. I was staying with them, they then offered me a job. I am now an attendant in the Laboratory.

At that time, sometimes when they go to the farm, if I want to cook, I will be thinking will they be willing to eat the food I have cooked for them because of my sickness. it was all in my thoughts...it was all in my thoughts. I cook sometimes and sometimes I will not cook...one of the women in the compound told me one day that I should not cook when visitors come, because they might not be 'able' to eat the food...the people living in our compound ate the food then...it's when we had visitors I did not cook...I felt bad... I even wondered whether my mother did not know how to tell me. And I could not ask my mother...I felt because I was her daughter that was why she asked that woman to do so...that is why I did not ask her...maybe she did not want to hurt my feelings. So, she did not stop me from cooking but asked the woman to talk to me... we had people coming...people in the neighbourhood to visit us. If visitors come, I cannot come out like I used to do because of the sickness. There was no way I could come out where people were gathered. They will insult me when I am not there, but I didn't hear them, but I am sure they did. But I was told they were saying urine is rushing out from my body. And I started feeling bitter...this was when I returned home. But in my husband's house, you know it was not in the same village as my parents. There were many things that happened. For instance, the woman in the village will come and say "why have you left her here. "Your son will not lack someone to marry, so why not send her away so you can marry another woman". So, I decided to leave, because I knew my parents will not refuse me...sometimes I felt bitter, at other times, I felt ...I didn't go to buy the sickness with money, so one day I know God will cure me. I don't know how I came about this sickness and this was not how I was born so one day I will get a cure...this is not how I will go home...I never felt like dying but I felt very bitter and sad about what people were saying about me and how they didn't want me near them. His own parents were not even bothered about me...separation from him was because of the urine... he never helped in anyway...on returning home with the condition... it was different, things changed for me. My parents did not bother with what people were saying, and they showed me love in spite of my sickness. I felt a bit relieved on return home, even though I was different. Unlike when I was there when no one bothered about me or stood by

me. The way people ran away from me while I was in my parent's house was not up to the one I experienced while in my husband's house. Even though I was different, I was better treated, so I felt welcomed and at peace. No one was willing to stand by me in their house, but my parents supported me...after the sickness came, my grandmother came from our village to live with me. She was the only one caring for me. There was only woman who sometimes if she meets my mother in the market would collect foodstuff from them to bring for me. She did this because she was used to my family before now. She will bring the food stuff for me...the only help came from my family, while living there. All the rags I used to stop the flow were my wrappers and grandmother's wrappers. No woman helped in any way, He never... he never wanted to come near me (sexual intercourse) again.... If he wants to come inside the room, he might come in and leave immediately or he will ask a small boy living in our compound to pick anything he wants from the room. Also after the problem started, I was no longer allowed to sleep on the bed I was made to sleep on the floor because they said I would destroy the mattress with my urine...he wanted me to leave not what because of what people were saying, but because he no longer wanted me because of my sickness... there was love before and we lived in peace, but he wanted me to leave because of my condition he rejected me...I lived in his house when I was leaking urine but they said they don't have the money to cater for my hospital bills. Yes, they said they don't have money, he also said he doesn't have money that he doesn't know the kind of sickness I had. Saying that it might be that my people don't want me to stay with him. I was just staying like that until one Sunday he said he cannot stay with me. The room is smelling, people cannot come for a visit in the house. I said, it is ok, I know my parents will not reject me. I started parking my things with the help of his mother. When we were done, I moved them to the road and went back to my parents.

But he came back after I was cured and discharged from the hospital, but my father asked him to leave. He told him... "Why have you come to see us, is it because she is cured now? If she had died is it her dead body you want to come and see in this house, what are you looking for here, do you want to destroy her again, is it because she is now healed, and you do not have a 'girl' again... If I ever see you again, I will call the police". So since then he never came back again till date. After that I moved down here. I never

loved him. I don't know how it happened...I never loved him, it's the pregnancy that joined us together... I never wanted him... it was just the pregnancy... I don't want the relationship again... I don't want any relationship again, if God says I will marry, I will...sometimes I begin to think and... I fear that the same problem can happen to me again. Even though people are coming, I have not agreed to anyone... (Silence)...I do plan to marry but not now... (Giggled)...All I am thinking about is how I can finish my school... the pain of the condition and the rejection has destroyed the desire for the opposite sex... the way people treated me, the hurts... the rejection... the pains I suffered from the condition has all destroyed any sexual desire ... but for now I want to finish my school. Yes! I am healed, no leakage again. I am enjoying the way I am, my body has gone back to normal. I don't have any problem. My only sickness is sometimes headache or fever. Now I am healthy, the benefits are many... I am now able to work and even support my family... all those who were laughing at me, now know it was for good... now see! I am different (laughed), even better than my life before I got the condition. After we left here my father died and so it's my mother alone I have, she used to help me, and I now have the opportunity to also help them at home with this work I am doing now. God has given me this work, so I am also trying my best to help them.

Before I got here... Initially I used to think I was the only one in the world with this... when I was at home and didn't know there was a cure for this. I used to think, which type of sickness is this. When I got here I was relieved when I saw other women in the same condition, my real fears came down. I stopped being ashamed, even if I was wet, I started feeling at peace with myself, I stopped thinking like I used to in the pasts, on seeing all the women like me. My fears all left, I felt relieved...one of the things that made me really fearful was that in one hospital we went to, they had said they don't give injections to people in our condition and there is no solution, except God helps you... before the urine can be stopped, but now all that is gone...my mother was the one washing my rags that were soaked with urine. Sometimes I will tell her not to worry, I would do it myself. You know when we were to come we were told we didn't need to pay for anything. My father then said, "In these days, is there anything that is free, is it really true that you go to a hospital and it is free" so we came with money. When we finally got here, he felt the money should be of benefit, since all my clothes had been

destroyed by the urine, they should buy me some new clothes. So, they bought me new clothes.

I learnt the sewing for one year. Sometimes if my dress is torn, I sew it. I can even sew simple dresses for myself. I knit hats. I bought a knitting machine, I knit sweaters and children stuff. I do sew for people...sometimes people will ask me to do something for them. Before I started work, I use to make them for sale. And people do buy... now that I am working, I do it on a smaller scale when I close, except for my schooling. When I finished learning, I went home and showed them what I did. I knitted a child's blanket and cap. I showed them the clothes I sew including the patch works and children dresses. They said their intention was not to stop me from coming, they were only afraid of me falling into something bad. They asked if I have the money to continue because they wanted to help me with some money to buy materials, but I refused. I told them that they have suffered enough for my sake and I appreciate, they should just go and help my siblings. I will do my best to help myself. At that time, we use to go and help some doctor's wives with chores and they give us money in return. I kept saving that money and ended up buying a knitting machine with it. When I bought it, it was 17,000 Naira and the sewing machine was about 20,000 Naira

I never knew I would become what I am today... the rehab helped me to see I could learn things...it provided me the opportunity to do something useful with my life. Because of my experience there like I told you I have gone back to continue my secondary education. I now know many more people... The time I spent there helped me to recover fully before even going home, so I was already strong before leaving for my village... it helped to build my confidence...I go wherever I want now without fear. I want to say this...even though my own was easy compared to others, many of them need help. Because of this problem, many cannot walk well, some have ear problems, they cannot hear well. Some cannot even see well. Because of too much thinking, some develop brain problems to the extent that they behave like mad people. Those of us in this condition...there are many other women with this problem in different conditions, others not knowing how they can receive help. I never knew I would ever be cured.

There is this old woman in my village, after I returned home that I was told had the condition since her first delivery and had nine children even with it. I went and told the family about this place, that they can take her. I kept going but her children said, she was already old and “they” will only “kill” the old woman if she goes for the operation. I saw even old women that were brought for treatment while I was here. They said after all, she had lived with it all these years, there is no point hastening her death. The woman is still alive...It is not that they do not have the money.... because some will say is an issue of money, no It is not the issue of money ...I didn't know what to tell them again to make them agree. The freedom I received is what I want every woman in my condition to experience. I never knew I could be cured, that is why I feel I need to tell others so that they can receive the same freedom I have received.

Appendix 1c - Story three: Loveth's story

Current continence status- mild leak

I gave birth three times; it was at my fourth that I had that problem. I started feeling pains in my stomach, so I went to the hospital that same day. When I entered the hospital, they said, “See, the child is coming out.” The child started coming out head first, that was around 4 p.m. When the head came out, it stopped there, it neither came out no went back in. The whole nurses spent that night on me, later, I felt as if my body no longer belongs to me. I will come down from the bed and they will pick me up and put me back. The next morning, they pressed my stomach like this (demonstrated how) and I started bleeding. Our road was bad then, so they put me on a motorcycle. If we reach where the road is very bad, my husband and my father will lift up like this (demonstrated how) until the rider passes the very rough spot that was how we were able to reach the side of road that leads to Saminaka. By the time we reached Saminaka, my vagina was already swollen so they say there is no way I can deliver on my own, they will have to operate, and we will have to put money down before the surgery. It was a

government general hospital in Saminaka...My husband had no money, my mother had no money...They insisted they must provide the money...We arrived Saminaka around 4 pm and they refuse to operate till we deposit money and I stayed like that for the whole night again until around 12 noon the next day before they did the surgery. My mother spent the whole day in Saminaka looking for money among relatives but couldn't get anything. She came back and begged the doctor and the surgery was done around 12 pm the next day. They removed the dead child and I was in a very bad shape... my life was in God's hand...It is when you come and touch me you would realize I was a human being...I was told I spent about two weeks before I became fully conscious, but I couldn't move. That was how I was... They had to be turning me from one side to the other...That was how bad I was...up to the extent the doctor became tired...to worsen it, the stitches came off and every time they come to wash it, they will be removing so much pus. I had to be taken to the theatre again. They doctor discharged us thinking that I was going to die, he never expected me to live so I was taken back home. When we got home, my people started applying hot water on me. One month, two months, I started sitting up, like child's play... Little by little I started putting my legs on the ground. About three months after, we went back, and they sent us here to Jankwano. We came on Wednesday not knowing that clinic days are on Monday. The day we got here, I could hardly walk, my people had to carry me, and we stood in the corner not knowing what to do until somewhere directed us. When we finally saw the doctor, I was given a date for surgery and when the day reached, I had my surgery, but it didn't work so we went back. After three months I came back again, and I was examined again, so I had to be going home and coming back. After some time, my people left me... They were tired. I was frying chin chin and people use to patronize me so that was how I used to raise my transport money. Sometimes I will have the money to come but the money to go back home will become a problem unless I get support from fellow passengers before I will be able to get back home. That was how I kept doing and gradually my strength was returning. Later I heard that they are going to teach knitting here, so I joined, and God helped me to learn. After my training I went back home and met my sister who allowed me to use her knitting machine. After harvest I got my own machine and people started rushing to me. Everyone that want something knitted, comes to me and later I got people that I was teaching. That is how my breakthrough came and I started

progressing. When I came back one time, I saw them producing pomade. I asked them to teach me and they taught me. Anytime I come and see something new, I will learn and take it back to the village. My market kept expanding. I didn't stop there, I later started a provision store, since I don't go to farm, I said I will use that as my source of livelihood. I bought a grinding machine and add to my provision store. I became so busy that I couldn't concentrate on the knitting again. That is why I cannot stay away from this VVF ceremony...because of all the rehab and this place has done for me...

When I went back home after removing the child, I was being helped, but they got tired. My parents and my relations said they are tired and left me. Again...during my sickness, my husband felt ill too and eventually died. When I was taken to the hospital where I had my surgery, he kept coming to the hospital to look after me. I was on admission there for about three months, because when the operation was done, the stitches got loosed and they had to be washing and dressing it and the doctor was not coming to the place because he was afraid, ...even the persons that were to do the dressing were reluctant to do so...it took them a long time to put me in shape fit for going back to the theatre. It was after the second stitching that I was taken back home. Not long after that, he took ill and died. That was how I had to go back to my parents' house... He died and left me with my parents and when they too got tired, they left me. I was now on my own, I was very weak to the extent that if I stand up, I will be very dizzy. But I had to force myself to be frying chin chin. Weak, soaked in urine and sick. I will send someone to buy flour for me; I will sit down and mix then fry it. With the help of God, any time I fry chin chin, people will buy it all. I will use the money to buy more flour the next day and that was how I kept going. Before the month run out I will have enough money to come to Jos and seek for treatment, sometimes if I tell them I am coming to Jos, they will just wave and say safe journey and I will carry my money and come. But today! People are coming to me with their problems and all sort of request. My relations and their children, my parents, everyone is coming and once I have it, I don't deny any of them.... I have seen hatred, at that time, all I had to do was just to cry... Even now when I recall some of the things I have gone through, I cry. If not for the grace of God, I couldn't have been what I am today... (Crying). That was what I went through...many difficulties...

People outside didn't stigmatise me, if they have done that, I wouldn't have known what my life could have been like today. Whatever I put out for sale, people come, and they buy. If they have not patronized me, I wouldn't have been able to come for treatment. I thank God because people did not run away from me...They were coming close to me, visiting and praying for me... At the time it was pouring much, when I get to where I want to sit down, I will fold a rag, put it under my wrapper and sit on it, when I stand up, and I will fold it and put it in a container. At that time, I was not going anywhere. But after I had my surgery and I started walking around, when I feel like urinating, I will squat and urinate so many people did not even know that I had it because you will never see me wet and up till today I still have it because it has not gone completely but people won't know. But if it is at night I can stand up several times and even now I can travel from here to our village (about 3 hours journey) and not need to use the toilet I am already married. I decided to go back to the second man that we had a child between us before I married my late husband. We are now together with our child... I am still leaking...No he doesn't complain... we do (sexual relation) without any problem...I have had three deliveries and got the problem at my fourth deliver but since I had the surgery, I stopped seeing my menstruation...since from that time...It has been quite some time and since then I have not had menstruation. The first child I had died after about a year, the second child died the same day...the third child was up to...two years before I became pregnant for this fourth delivery that caused the problem... so from that time, no more menstruation...I am always ill, always ill, always ill...almost every week I will fall ill...up till now I am not feeling well...I'm not well...Initially I was asking God to just take my life, I wanted to die so I can rest but now, I can only worry because of the illnesses that I am constantly facing. But now if it is concerning means of livelihood, I can give to people...I can now feed and clothe myself, I can meet the need of my child, I can only thank God...I am only praying that God will give me long life so I can educate my child so he too can move up in life

Honestly, if it is the issue of leaking urine, it is only when I tell somebody that I am not healed, even today, we can stay with people for a long time, unless I tell them, they will not know. Another thing is that right from the start, I don't use rags. When I see people using rags I use to tell them that rags have their own problems...rags have many

problems...rags sometimes can damage your private part... I encourage people to get use to their system so as to be able to know when they need to go and urinate. They need to discipline themselves to squeeze themselves in so as to keep the urine from dripping... when you keep holding yourself, after some time you will feel the urge to urinate...then you will go and squat and release the urine...you have to keep disciplining yourself to be able to do it...it will become a part of you... Okay, I did that for myself and it helped me...if you are squeezing yourself, when you feel the urge you can then go and urinate...me now! ...honestly, I can travel from here to Saminaka without leaking urine...no not even a drop. I do travel from home to Jos and spend some time going around before I feel like urinating but if I am traveling and suddenly feel like urinating, I will ask the driver to stop so I can go ease myself...if I find somewhere suitable to do so... before we came here, I was always inside the room...not coming out. They placed a polythene sheet on the floor and place rags on the sheet and I laid on it...even to eat, they would have to bring the food to me in that position, there was no going out at that point

When we first came here been new we didn't know anyone so, we went to the OPD and sat down, we were given a letter to bring to the pastor which we did. The pastor told us that our case is a difficult one because nobody will like to host us in his house, but he told us that there is a place here where we can stay so he took us to the VVF village that was in the evening. We came and sat in the sitting room and my mother put a wrapper down for me which I sat on. Later a woman came out and saw us, she asked who the people sitting outside in the cold are because it was cold at that time. She went and opened a room for us, asked us to enter and we entered in there. When they finished cooking, the woman went and collected food and brought the food to us. In the morning, she did the same thing. We begin to wonder how the woman is cooking and bringing us food as if she knew us before not knowing that they do cook for the patients. When she came the third time, she asked my mother to follow her, so she can show her how they collect food here. My mother followed her, when she came back she told me that they cook food for patients here. I asked, "Cooking food for patients? Do they pay? See how good the food is." I kept thinking of how the hospital can give that type of food to patients for free. I was examined and after one week, I had my first surgery, but it

didn't work so I was told to go and come back after three months. When we came back, I had another surgery, but the leaking did not stop completely. All the women we had surgery with on that day were totally healed except me. I spent the whole day and night without sleeping. I was just crying...Am I the only one that God doesn't like? I had the first one which failed and this second one was not successful either, I kept asking myself how I can live again... I went back home... I started my own version of bladder training. Because I wasn't going anywhere at the time, when I want to sit down, I will take a rag, fold it and put it under my wrapper when I stand up I will soak it. I kept trying to learn how to hold the urine and gradually I started feeling like urinating and when that happens, I will go to the bathroom and urinate

There is a remarkable difference; at that time, I rush to the bathroom every minute without any break but now I sometimes do forget that I have something...I don't think there is anybody that is as happy as I am. My only problem as I sit here now is that of constant ill-health. I cannot eat properly now, even though now, I have sufficient food...I cannot eat...I only eat very little. If you take a little serving spoon of food...I cannot finish it...I don't know if it has to do with the surgery because I use to eat very well. I lost my appetite when I started recovering from the surgery. It is about ten years ago now...I use to tell them, but they sometimes say their main concern is VVF no other illness. That is what I was thinking of now hoping I will get a card from here that I will take to the OPD. I say I am healed...Yes. If I can travel from here to Saminaka without leakage I can say I am healed. Before, I cannot stay indoors for a few minutes but now, I can say for hours without visiting the rest room. I can enter a vehicle and travel to wherever I want. I have to say that I am healed...am I not healed? I am...

When I first came in (rehab centre) and saw the equipment, I told people around that I am happy I have gotten a source of livelihood. I was asking the mama there when we are going to start but she said they need to fix one or two more things first. I left for home; by the time I get back, they have already started with the first set. Just when I was to start, I became ill and had to be hospitalized. When I got better, I went home and came back when I got better but by then, I have lost the chance of joining the first

set, so I started along with the second set. I started with sewing, but I discovered I am not catching up, so I went back to the knitting group. For the first three weeks I was not able to follow what was happening, so I got very angry and started saying how can I go home without learning anything? One day when I came in and sat down, they called for breakfast, I refused to stand and leave the machine, so they kept my breakfast aside. During lunch, they asked us to go for lunch, I didn't leave the machine, so they kept my lunch by the side. When they were about to keep my supper aside, I stood up and joined them. From that day, it was as if my head was opened. The woman in-charge of the knitting section will send us to the maternity ward to go and display our knitted materials for sale. Any day I took my own there, I came back with between three to four thousand but if somebody takes theirs, he comes back with about one thousand two or one thousand five hundred Naira. One day she asked if I will be taking her things out for sale and I said I am not here to sell things. If I knit something and take it out, women will be asking me to knit this knit that for them, so I will go and tell her what the women wanted. At that time, even if it is my shoes that cut, I will take it to her and tell her that my shoe is cut, and she will buy another one for me... When I saw them making cake, I jumped into that one too to learn. Now that I am home, people come to me for birthday cakes and cakes for other occasions, but I don't make wedding cakes because I don't think I can do it.

My parents or relations did not contribute anything to my training...they even wanted to stop me from doing a freedom ceremony, they were asking who will stand for me, but I told them I have the whole world... I remember something that happened one of those times... It was when I got home and told them that I am going to have surgery and nobody paid any attention to me so I asked our youngest sister to follow me but I had no money so I followed people and started begging and people started giving me one measure of corn here, two measures of maize there, someone will give me four another will give me five. When I sold those and other things, I took our youngest sister and set out for Jos. Nine of us had surgery that day. That same evening, I sat up on bed and asked her to give me water and something that I can eat. She gave me pap (gruel) and just when I started drinking it, my ribs started to pain. I started shouting. If they give me an injection, it will go down after a little while it will start again. That was how it

continued up till the time of my discharge from admission. The person I brought with me is just a small girl and here I am crying day in day out, I didn't know what to do. If I start shouting, the girl will start crying so I told her to put our things together, so we can move to one of our aunt's, in case I am going to die, let her figure out what to do. She put our things together, and I struggled to reach the gate of the hospital from where we got a motorcycle that took us to Bukuru. When we reached there, the aunt who is a medical person started giving me a variety of drugs and IV fluid, but nothing worked so she brought me back here and the people here told her that I absconded, so they will not receive me here because they have already returned my card to the OPD. But there was a white lady here who went and brought back my card. There was a ceremony around that time so people that came from our area took the little girl that was with me back home leaving me alone here. I was very sick, I couldn't stand up, I even told them that I don't have money, but they said they will pay her transport money when they get home they will ask for reimbursement. They left me like that on the bed, there were some of my cloths that were soaked by the tap and I couldn't get up and the girl is gone. One woman came and asks, "haven't I seen you with a little girl?" I answered yes and wanted to know where the girl was, and I told her she has gone home. I told her "when you don't have your own, what can you do". That woman went, took those clothes, washed them and put them on the line to dry. She went and brought food for me, just when I was about to start eating, I started vomiting. She went and prepared some pap for me and ask me to take and I took. She asked where my room was, and I showed her. The next day she came in with some pap again which I took. I vomited the moment I finished taking the pap. She went and reported to the nurses and they asked her to take me to them. When she took me there, I was admitted, and many doctors were gathered around me performing different types of examinations. They brought a carton of drip and start giving me IV fluids. That woman started nursing me... I never knew the woman before, but we spent two days with that woman helping to care for me before my aunt from Bukuru came. When she came and saw the condition I was in she was shocked she asked about my sister and I told her that she has gone home four days ago. I told her that they took the girl again away because they know I have nothing and that I am no longer useful to them that was why they took her away and left me like that. If they cared, realizing she was just a little girl and could not cope with caring for me, they would

have sent someone more matured to take over. At that point I started crying, but she encouraged me with some Biblical passages and not to give up hope. The next day being Sunday, she went to our village and looked for my mother and asked her to follow her. That was how she brought my mother here.

The freedom ceremony after our training... Ha! That was what gave me strength when I went back. Those items that were given to us were what encouraged us to get into the business which I am still doing. And that cake! I used to think that cakes are always brought from outside the country, I never knew that they make cakes here in Nigeria and now I am the one making cakes!! Even if they wake me up from sleep and ask me to make cake, I will make it. Those items that we got encouraged me to start... definitely, apart from the item, I was given transport money that will take me home, it was a big encouragement the benefits of the rehab on my life... it is like this sickness became a blessing to me...The people I never expected I will have contact with became my business partners. Because in my petty trading I deal with all sort of stuff, different cadres of people...even educated people do come to pick things from me some will even pick on credit. Some will come asking for loans. Even the people I never expected will come to me do come...

Our going back home... was because they drove us away from here... not because we wanted to go back, really, we did not want to leave this place. You needed to have been here to see how we were... we even had a women fellowship group here, we will sit down here and learn songs that we will go to church and sing on Sundays...at that time... They had to tell us, they no longer wanted to see us here again by the next day...before we started leaving for our homes... when I returned home, Ha! Things were different... there were real changes...Yes, there were people who came and learned from me... the people that rejected me they started coming, there was a woman that hated me, but when I went back home I use to cook soup for her every week. Every Saturday, I will do that...when I was ill, my household items were distributed by relations among themselves as if I was dead. "When is she going to get up and do something" When I started getting up, they will ask me to buy every little item that I am going to use. If I

want to take a dish to mix my chin chin inside, they will ask me to go and buy my own dish. If I touch that pot, they will ask me to buy my own pot. That was how I started putting things together again. In my parent's house but now that I have put the things together, they are coming to pick or to borrow.

The rehabilitation centre has added to my life...I don't know how to class a woman that is sitting down without a vocation...can you hear me...If you don't have a vocation, you are not really living, no matter what you do, vocation is always important and useful. If not because of vocation, I could have gone mad by now. Who is going to help me, nobody is going to help me because I have already seen it with my eyes, but the grace of God helped me by giving me a trade that I am using to eat and drink today. It helped to redirect my thinking away from pity and bitterness to seeking a livelihood to help not only myself but those around me. I think of nothing now but how to help others...sometimes I think over it (condition)... I have had first it didn't work...and second surgery but I am not totally healed, sometimes I think if I give myself enough time before coming back, they will say the place has healed up and I may be lucky. So, some day I am hoping that they will say they will be able to try again...I want to advice women to come out and learn a trade. Everyone woman should come forward... You don't have to look up to your husband for every little thing...That is not living. You see the husband I am with now; many people are coming to advise me not to support him that much...that it is not right to support your husband... but I will always ask them "what about the support he gave me?" He is the one that goes to farm and bring food for me in the house. If he brings the food, should I also tell him to give me this and give me that? No, that is not right. Everyone should contribute something. He is helping me a lot, so I will also help him. He goes to fetch firewood for me, he helps me with the washing... If you sit down and wait for him to provide everything, he will grow tired. Even if he doesn't complain, someday those same people will start complaining.

APPENDIX 2 INSTITUTIONAL ETHICAL APPROVAL LETTERS

Appendix 2a - Ethical Approval letter, University of Hull



PRIVATE AND CONFIDENTIAL

Hannah Degge
Faculty of Health and Social Care
University of Hull

**Faculty of Health and Social Care
Research Ethics Committee**

T: 01482 464680
E: J.Dyson@hull.ac.uk

REF 206

07 December 2015

Dear Hannah

RE: The Social Reintegration Experiences of women treated for obstetric fistula in Nigeria

Thank you for your satisfactory responses to the points raised by the Ethics Committee. I am pleased to be able to grant Chair's approval as per the Terms of Reference.

I wish you every success with your study.

Yours sincerely

A handwritten signature in black ink, appearing to read "J. Dyson".

Dr Judith Dyson
Chair, FHSC Research Ethics Committee

Cc file

University of Hull
Hull Campus
Hull, HU6 7RX
Campus switchboard
01482 346311
www.hull.ac.uk

Appendix 2b - Ethical approval letter- study site



BINGHAM UNIVERSITY TEACHING HOSPITAL

#23 Zaria By-Pass, Behind Polo Field
P.M.B. 2238 JOS-PLATEAU STATE.

0818-160--0465

E-mail: evangeljos@yahoo.com

website: www.ecwabhuth.org

HEALTH RESEARCH ETHICS COMMITTEE.

NHREC/21/05/2008/00208

2nd February, 2016

NOTICE OF FULL APPROVAL AFTER FULL REVIEW BY THE HEALTH RESEARCH AND ETHICS COMMITTEE:

DR. DANIEL MWANMUT
Board Chairman
MB, BS, MSc, D Occ Med
DTCH, DTM & H.

RE: THE SOCIAL REINTEGRATION EXPERINCES OF WOMEN TREATED FOR OBSTETRIC FISTULA IN NIGERIA

Name of principal investigator:

Hannah M. Degge

Address of principal Investigator:

Faculty of Health and social
Care University of Hull, United
Kingdom

Date of recipient of valid application:

20th January, 2016

Date of meeting when final approval determination of research was made: 1st Feb, 2016

DR. M. DANKYAU
Chief Medical Director
BM, BCh, FWACP

This is to inform you that the research described and in the submitted protocol, have been reviewed and approved by the Health Research Ethics Committee (BHUTH).


DR. S. MIKAH
Chairman, MAC
MBBS, FWACS

This approval is effective from 2nd February, 2016 to 2nd February, 2017. If there is delay in starting the research, please inform the HREC so that the dates of approval can be adjusted accordingly. Note that no participant accrual activity related to this research may be conducted outside of these dates. All informed consent forms used in this study must carry the HREC assigned number and duration of HREC approval of the study. In a multiyear research, endeavor to submit your annual report to the HREC early in order to obtain renewal of your approval and avoid disruption of your research.

Find attached a report format to be used in writing your report.

MRS. H.R. ATTA (JP)
Director of Admin.
BSC, RNIM, AHSAN

The National Code for health research requires you to comply with all institutional guidelines, rules and regulations and with the tenets of the code, including that all adverse events are reported promptly to the HREC. No changes are permitted in the research without prior approval by the HREC except in circumstances outlined in the code. The HREC reserves the right to conduct compliance visit to your research site without previous notification.


Dr. G. Chima
Chairman HREC BHUTH

Jesus said "I have come in order that they might have life, in all its fullness" (John 10:10 TEV)



Title of the study: The social reintegration experiences of women treated for obstetric fistula in Nigeria

You are invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what will it involve. Please take time to read the following information carefully. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not to take part. Thank you for reading this.

What is the purpose of this study?

The purpose of this study is to explore the experiences of the women who have had fistula repair and rehabilitation; to understand how this has contributed to their reintegration.

Why I have been chosen?

You have been chosen to take part because you have undergone fistula repair and rehabilitation, hence you fall into the group I wish to include.

Do I have to take part?

There is no obligation to participate. It is up to you to decide whether or not to take part. If you wish to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason.

What will happen to me if I take part?

You will be interviewed by Hannah Degge (researcher) and another person that speaks Hausa very well in order for us to be able explain questions and understand your

experience very well. For this I will ask for your permission to audiotape the interview, which will last for between 60 to 90 minutes

What do I have to do?

You do not have to do anything; the interview will be done at a convenient time for you and in a comfortable place we would both agree upon in the hospital.

What is being discussed?

You will be invited to share your experience regarding the topic of the study. The conversation will be recorded on a tape recorder for analysis but it will not be made available to anybody except Hannah Degge (researcher) and her supervisors. The tapes will be destroyed as soon as transcription is done. You will be given the opportunity to see and approve the transcribed interview if you wish.

What are possible disadvantages and risk of taking part in the study?

The study seeks to gain better understanding of the experiences after fistula treatment on return to the community. You might feel emotional remembering your past experiences. However, if at any time you feel you are at risk for taking part in this study, you should feel free to withdraw from the study any time you wish. If you decide to discontinue all data collected up to the point of withdrawal would be kept. But all information given at the point of withdrawal will be deleted. Note that all information you are going to provide including any inconveniences you may have felt will be strictly treated with high confidentiality.

What are the possible benefits of taking part?

The possible benefits are that the study will help provide a better understanding for the hospital in caring for women with fistula, it would also help community members relate better with women with fistula and help to prevent its development. Furthermore, it can assist our policy makers in taking decisions concerning fistula care.

Role of husband/support provider?

As it is our custom, in case you need to take permission from either your husband or someone you live with. I would kindly require you to discuss and agree with them over

this, before taking part. If you think you require support in doing this, a copy of this information sheet can be given to them or I can talk with them over the phone to explain what the study is about.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the study will be kept strictly confidential. Any information about you and the data you will provide will be anonymised so that you will not be identified in any way.

What will happen to the results of the study?

The results will be used as part of the fulfilment of my PhD study and conference presentations. It will also be used for publication so that a wider audience will be informed of the findings.

Who is organizing the research?

The research is being organized, as part of a PhD at the University of Hull and the host in Nigeria is Bingham University.

Who has reviewed the study?

The Research and Development Department of the University of Hull have reviewed and approved the study. The study has also been approved by the Health Research Ethics Committee, BHUTH, Jos.

Contact for further information

Hannah M Degge (Researcher)
Department of Community Medicine
College of Health Sciences
Bingham University
Bingham University Teaching Hospital
Jos

Tel +234813045099

You will be given a copy of this information sheet and your signed consent form to keep

APPENDIX 4 - CONSENT FORM (English version)



CONSENT FORM

Title of the study: The social reintegration experiences of women treated for obstetric fistula in Nigeria

I volunteer to participate in a research project conducted by Hannah Degge, a PhD student from University of Hull, UK. I understand that the project is designed to gather information about experiences of women with fistula and their families. I will be one of the people to be interviewed for this research.

Instructions

Please tick each box when you agree with the statement attached to it Tick box

- | | |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|
| 1. I have understood the information given to me about the research project and I have been given a copy of the information sheet to keep. | <input type="checkbox"/> |
| 2. The purpose of research has been explained to me and I have had opportunity to ask questions. I understand the procedures which will be involved, and these have been explained to me. | <input type="checkbox"/> |
| 3. I understand that my involvement in this study, particularly the information collected will be anonymised and kept confidential. It has been explained to me what will happen to the data once the research project has been completed. | <input type="checkbox"/> |
| 4. I understand that the research forms part of the requirements for a Doctoral degree in Health and the findings may result in publication. | <input type="checkbox"/> |
| 5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving reason and without my legal rights being affected. | <input type="checkbox"/> |
| 6. I agree to take part in the above study | <input type="checkbox"/> |

Name of Participant Date Signature

Name of Person
Taking a consent

Date

Signature

Researcher

Date

Signature

APPENDIX 5 - INTERVIEW GUIDE (English version)

Experience of fistula survivors

Introduction

For the purpose of this research, this session is to allow you to tell me about your experience of having a fistula and coming back to resume life after treatment. I would be pleased if you could do this by telling me your own a story

If you want, we could split the story into situations to help you remember. Again, I could from time to time ask you some questions to clarify anything that is not too clear

Thank you for your time and patience.

Opening question: Kindly tell me your story about your life with fistula, how did you get it, what happened to you afterwards.

A. Situation one

- Can you please tell me the story of how you developed a fistula?
- Can you tell me your story of how life was living with a fistula?
- Probe: how did it affect your relationship with your husband; describe what happened

How did it affect your relationship with parent, friends, and community/neighbours?

- How did you feel about life generally?
- Can you tell me how you cope living with a fistula? Tell me about the strategies you developed

How effective do you feel your coping strategies in helping you to cope?

B. Situation two – treatment

- Tell me about your treatment experiences
- Do you consider yourself cured/ no more leaking?
- If you do not consider yourself cured what issues still remain and how are these impacting on your overall well-being?
- What does being well again mean to you?
- Post repair care- tell me about your rehabilitation experience

- What role did your family play in this process?

C. Situation three - going home (transition)

Preparing to leave the centre to return home

- What were your expectations in returning home?
- What was involved in this preparation; what name was given to this process;
- Freedom ceremony - what happens? Did this help you and if so how, or if not what else do you think might have helped you?
- Finally going home; where is home, what did this mean to you, what was involved

C. Situation four - resuming/returning to life (reintegration experience);

Tell me the story about returning to normal life

Role of family & community

- Getting home; what happened, who received you?
- Living at home; adjusting; how are your feelings, what happened; who was involved?
- Describe life since you returned, is this normal or better or not; what makes you feel that way?
- What / who has contributed to making this possible or not possible?
- who were the community people/group (name them) that supported you on return (were they the same people or different that helped you when you were with the problem)
- What specific role did community members play
- Were there any persons (name them) that did not support you, or you consider a hindrance to normal life
- What did these persons do?

Coping mechanisms

- In returning home, how did you adjust to life?
 - Can you tell us me what ways you have developed in coping with daily living? (probe are they the same as when you were living with fistula)

- What roles did play (family, friends, and community) play in coping with daily living?
- Can you explain how effective were all that you have discussed in helping you get by?

Sexual and reproductive life

a. if married

- What is your relationship with your husband (first or second)?
- Do you still relate (sexually) as husband and wife?
- Are there any issues of concern with this aspect of relationship with him?
- What are the things you feel could have helped you better adjusted to life now?

b. If not married

- Can you describe in what ways fistula has affected your relationship with the opposite sex?
- How do you feel as woman with the changes fistula has brought to you?
- Are there issues of concern in relation to future relationships as a woman/ being a mother?

Reintegration experience

- Looking at the first day you were told you could go home and where you are now, what has changed?
- Can you recount how your day went yesterday at home; a typical example of your daily life
- What role did the rehab contribute to resuming life?
- Are there any benefits from the rehab, can you describe in what way?
- Are there areas of your life you still have fear about; give a typical example of such
- In your opinion who should take responsibility for you resuming life normally
- Talking about your expectation when you were returning home; were they fulfilled? What hopes do you have for the future?

Women with persisting incontinence (do you still experience leaking, if yes proceed to questions)

- What are the challenges you still face in spite of going for a repair (probe: role of family/community; relationships/ sexual and reproductive life)
- Kindly share any particular story of your experiences since you returned

Finally, is there any other thing you would like to tell me?

Thank you very much for your time.

B. DEMOGRAPHIC DATA/INFORMATION

1. Age at fistula development.....
2. Current age.....
3. Marital status (while with fistula).....
4. Current marital status (after treatment)
5. Number of wives husband has..... Which position...
6. Employment status.....
7. Educational status.....
8. Number of living children..... Number of children after repair.....
9. Home before fistula.....
10. Current home.....
11. Years living with fistula before repair.....
12. Years since treatment/returning home.....
13. Current continence status, leaking: Yes..... No.....